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Impact of chronic illness in women with Human T-Lymphotropic Virus (HTLV)

Impacto do adoecimento crônico em mulheres com Vírus Linfotrópico T Humano (HTLV)

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ABSTRACT | OBJECTIVE: To analyze how the changes caused by HTLV impact the daily lives of women and the ways of coping with the presence of the virus. **METHOD:** Qualitative descriptive research was carried out using secondary data extracted from the research project database entitled "Experience of sexuality: representations of people seropositive for HTLV." Data collection was carried out with 12 HTLV positive women seen at the infectology clinic of a University Hospital in Salvador, Bahia, Brazil, and at the Testing and Counseling Center (CTA) in the city of Santo Antonio de Jesus, Bahia, Brazil, using the Collective Subject Discourse as a methodological strategy. **RESULTS:** The testimonies and speeches of HTLV seropositive women reveal the stigma experienced by them, the withdrawal of friends and family after the diagnosis of HTLV, and the negative impact of these for women. Concerning coping with circumventing the stigma, women hide details related to HTLV infection or even completely cover up their serological condition, even for their family members. **CONCLUSION:** Thus, it is clear that HTLV impacts women's daily lives living with the virus. Thus, the health care provided should not be based only on physical well-being but also on their biopsychosocial well-being, thus contributing to coping with the stigma in the daily lives of HIV-positive women.

DESCRIPTORS: HTLV virus. Social stigma. Women.

RESUMO | OBJETIVO: Analisar de que modo às alterações causadas pelo HTLV impactam no cotidiano das mulheres e as formas de enfretamento a presença do referido vírus. **MÉTODO:** Pesquisa descritiva qualitativa realizada com utilização de dados secundários extraídos a partir da base de dados do projeto de pesquisa intitulado "Vivência da sexualidade: representações das pessoas soropositivas para o HTLV". A coleta de dados foi feita com 12 mulheres HTLV positivas atendidas no ambulatório de infectologia de um Hospital Universitário em Salvador/BA; e no Centro de Testagem e Aconselhamento (CTA) do município de Santo Antônio de Jesus/BA, utilizando como estratégia metodológica o Discurso do Sujeito Coletivo. **RESULTADOS:** Os depoimentos e falas de mulheres soropositivas para o HTLV revelam o estigma vivenciado por elas, o afastamento de amigos e familiares após o diagnóstico do HTLV e o impacto negativo para as mulheres. Quanto às formas de enfrentamento para driblar o estigma, as mulheres ocultam detalhes relacionados à infecção pelo HTLV e encobrem totalmente sua condição sorológica, até mesmo para seus familiares. **CONCLUSÃO:** O HTLV causa impactos no cotidiano das mulheres que convivem com o vírus. Assim, a assistência de saúde prestada deve ser baseada no bem estar físico e biopsicossocial, contribuindo assim, com o enfrentamento do estigma no cotidiano da mulher soropositiva.

DESCRITORES: Vírus HTLV. Estigma social. Mulheres.

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Introduction

The human T-cell lymphotropic virus (HTLV) comes in four types HTLV-1, HTLV-2, HTLV-3, and HTLV-4. HTLV-1 is more prevalent in the world and is associated with pathologies such as adult T-cell leukemia/ lymphoma (ALT) and tropical spastic paraparesis (TSP) (neurological disease), also known as HTLV-1-associated myelopathy (HAM); HTLV-2 has a lower risk of triggering diseases, but there are reports in the literature of sporadic cases of its association with myelopathy, predominant sensory polyneuropathies and inflammatory myopathy; types 3 and 4 were discovered in Africa.[1] Its transmission takes place vertically, horizontally, and parenterally.[2] From 5 to 10% of those infected, at any given time in their lives, develop some disease related to HTLV.[1]

HTLV infection presents itself as a chronic condition, with or without clinical manifestations. Currently, there is no specific treatment aimed at fighting the virus, and although most carriers remain asymptomatic, seropositivity by itself represents a great impact on their lives, as there is always the possibility of developing a disease.[1]

The chronic disease makes people experience changes in several aspects of their lives, such as economic and relational difficulties within the family, incapacity for work, and dependence on other people.[3] In this way, these people's lives are gaining new contours, a new way of relating to the world around them, reassessing concepts, values, and beliefs, reviewing postures, behaviors, and attitudes towards the new context.

These changes can occur together with feelings and perceptions of loss, fear, and anxiety, generating intense suffering for the patient. In addition, the HTLV-associated neurological complex, due to its probably immune-mediated pathogenesis, can be treated like other immune disorders of the nervous system. In the case of HTLV, the person affected by this virus may face impaired physical conditions such as postural, locomotion, mobility, loss of anal, and urinary sphincter continence, which contribute to the degradation of self-image and self-esteem of people.[3-5]

Recognizing the HTLV as a virus that causes chronic diseases, which can affect the physical and neurological condition, contributing to the degradation of women's self-esteem, we sought to analyze how the changes caused by HTLV impact the daily lives of women and the ways of coping the presence of the said virus.

Methods and materials

This is a descriptive study with a qualitative approach, carried out using secondary data extracted from the database organized for the research project entitled "Experience of sexuality: representations of HIV-positive people for the HTLV." Data collection for the larger project took place at the infectology clinic of a University Hospital, a Reference Center for the treatment of people affected by HTLV, located in the city of Salvador/BA; and in the municipality of Santo Antônio de Jesus/BA, through people registered at the Testing and Counseling Center (CTA), in the period between March and September 2011.

Twelve women are seropositive and symptomatic for HTLV infection who attended the services mentioned earlier participated in the research, with the following inclusion criteria: being adults, diagnosed with HTLV seropositivity for at least two years, and spontaneously accepting to participate in the study. Exclusion criteria were: being asymptomatic HTLV positive women and having a serological diagnosis for less than 02 years.

The collection technique used was the in-depth interview, which allows access to difficult data to obtain through direct observation. The interviews were recorded and later transcribed for better analysis and preservation of data reliability.

The Collective Subject Discourse (CSD) was the chosen methodological strategy for data analysis, as it consists of a single homogeneous synthesis discourse written in the first person singular, the thought of a collectivity, distinct subjects.[6] For this strategy to be put into practice, methodological figures such as Key Expressions (ECH) and Central Idea (CI) are needed. The key expressions (ECH) correspond to excerpts or literal transcriptions of the speech, highlighted by the researcher, revealing the discursive content's essence. At the same time, the Central Idea (CI) describes the meaning of the analyzed discourse as succinctly and reliably as possible. This idea is not an interpretation but a description of a statement or a set of statements.

The consolidation of the DSCs was ordered in the steps of transcription and reading of the interviews; identification of the central idea of the speeches; assignment of key expressions to identify central ideas; a grouping of key expressions by approximation of meanings; organization of speeches and discourse analysis, conforming the DSCs, namely "Hiding about the HTLV"; "Social death: separation from family and friends"; "The psychological impact of the HTLV"; "The divine and the family in confronting HTLV."

This study respects the aspects involving research with human beings through the project's approval by the Research Ethics Committee of the Hospital Complex Professor Edgar Santos under protocol No 116/2010, and request the study participants to sign the Term of Free and Informed Consent.

Results

The predominant age group of study participants was between 50 and 59 years (33.3%). As for education, those with primary education predominated (58.3%), and 33.3% reported being married. Regarding race/color, 66.6% declared themselves brown.

The following speeches consist of women's statements about the changes caused by HTLV seropositivity. These changes govern the way of living, are present in the bodies and the social relationships of these women. Therefore, they determine the way of thinking, acting, and interacting. They determine how they are inserted in society and how their social reality is constructed. The speeches reveal the stigma experienced by women, the distancing from friends and family after the HTLV diagnosis, the negative impact of these on women, in addition to reporting the ways that women use to strengthen themselves in order to face the new situation that is HTLV illness and its consequences.

First Speech - Concealment about the HTLV

> *I avoid commenting, I don't tell everyone that I have a problem, I don't reveal the diagnosis to other people; because sometimes people don't understand, it's very critical: "because she had more partners because she had relationships with the wrong people," so I prefer to avoid. I don't feel good about talking. I feel embarrassed, afraid. In my house, my children know I have a disease in my blood, but I try not to comment. I always try to run away, not go into details; my sisters and my mother don't know, they wouldn't understand, maybe discrimination would come from them without understanding why. After all, there's still a lot of prejudice, I've been through it, and it's terrible; someone says, "Oh girl, I heard that this disease you have is hopeless, isn't it?" A daughter-in-law who lived with me left everything mine separate, clothes, cup, fork, separated everything. If I say what I have, then I'm really going to be excluded from society. So I don't say what I have. If the person looks for it, I say it's a problem with nerves, so I don't go into details.*

Second Speech - Social death: distancing from family and friends

> *Friendships... friendships all moved away from me, they stopped talking to me, when people get sick they lose everything, they lose the friendship, they run out of money, they lose everything in life. Most of my kids don't care about me; it seems that I don't exist, I have 10 children, and I see myself alone. I live alone, God and me, and I live as long as God wants. When I was healthy, everyone would see me, or even when they didn't come, I would go, but now I'm not able to go. "It takes me 3, 4, 5 months without seeing them. Some still come to see me; others don't even look at the side where I live."*

Third speech - Psychological impact of HTLV

> *My life changed. I panicked! When (we) discover it's a disease that has no cure, the person despairs; I don't even like to remember. I was nervous, I was amazed! The first sensation you have is to isolate yourself, cry, cry until you can't anymore. I went into depression because the first thing I thought was that life doesn't exist anymore. I lived indoors. I didn't want to go to the doctor. I'm even taking depression medication now, sleeping medication too. We feel very useless, we lose confidence. I found myself in a wheelchair, a person who did everything and now depends on others to take a shower! Do you know the value of my life that many gave me? Zero. I also gave myself zero. After I got in the wheelchair, I've tried to commit suicide three times. It's so much that I feel like I'm going to lose my mind, you know? There are days that if I could, I wouldn't get out of bed; I like being alone, not talking; I've lost the joy of living. I don't have that same joy anymore.*

Fourth Discourse - The divine and the family in coping with the HTLV

> *I only have one plan, fight for life! After all, my only joy is "my children," so wonderful people who encourage me, special, trustworthy people. If God is not in control, we do not have the strength to support, whether HTLV or whatever the disease is, everything has to have God. Without Him, we are nothing; we are nobody. And that's where I invest my strength. I ask Him to calm me down, take away what I don't like, take away this stress and make me a calmer person. If it's God's will, I'll be fine. Nothing is impossible for God. Even though the doctors say there is no cure, faith is in Jesus, the doctors' doctor. I believe I will be healed in Jesus' name.*

Discussion

In the first speech, it is observed that the discovery of the virus causes HIV-positive women to experience stigma, whether from the family or society, as she reports: "I do not reveal the diagnosis to other people, if I say it, I will be excluded from society." Thus, these individuals choose to hide their seropositive status. Teixeira et al.[7] define stigma as a physical or social mark with a negative connotation that leads the bearer of this "mark" to be marginalized or excluded from some social situations.

The person, especially the woman with the virus, appears as endowed with behavior or attitudes inappropriate to social well-being. Still, they consider that the lack of clarification is, even today, largely responsible for the conflicting situations experienced by people who have some type of sexually transmitted disease.[7]

Furthermore, the speech demonstrates that the disclosure of the diagnosis was made only to some family members, and even so, not all data were declared. This silence is adopted in combating the criticisms that emerge when the diagnosis is revealed, mainly because it is an infection that is also sexually transmitted.

In this way, the attitude of omitting details or concealing the diagnosis concerning the virus infection is consolidated, not only for the family but also for friends. This strategy aims to protect itself from criticism or how the family and its network of relationships would react, as it is a sexually transmitted virus.[3] The silencing of the serological condition is an attempt to protect the eyes and judgment of others. At the same time, it grants them a status of normality concerning the people around them.[8]

The participants denote that prejudice associated with HTLV can arise from their own acquaintances for not understanding the disease. This rejection usually results from the semantic similarity of the virus with HIV and the perception of the disease (incurable and sexually transmitted). That brings a series of discriminatory concepts, socially embedded, developing thoughts that these people are not worthy of respect, as they were irresponsible, promiscuous to the point of being infected. Therefore, those affected feel hurt, ashamed, and guilty for having acquired this disease.

The feeling of sadness embedded in the speakers' report is also noticed due to their own families' lack of support and understanding. Prejudice is evidenced by the daughter-in-law's attitude, who lives in the same house, separates everything from her mother-in-law fearing the contamination.

The speech also shows that symptomatic people for HLTV are viewed with discrimination. They are the target of prejudice due to their health condition. Because of the physical signs present in the sick individual, the esthetic body expression is not viewed favorably by society. These manifestations flee from a socially accepted individual model.[9]

Thus, in an attempt to rule out the possibility of negative judgments regarding their serological condition, symptomatic HTLV seropositive people justify that the impairment and/or limitation presented is due to another problem other than HTLV.[3] The presence of this virus is a remarkable event, and a focus of new directions as a new way of life begins. This new life is full of stigma and prejudiced attitudes, which bring feelings of impotence, guilt, sadness, resentment, and shame.

In the second speech, it is possible to capture that after discovering the HTLV, there is the removal of people who were previously considered close to the affected woman. The findings corroborate Souza et al.[10], who states that the diagnosis of an STI for most women results in negative feelings and fear of abandonment by society.

People affected by HTLV experience and suffer stigma, whether from family members, sexual partners or friends, or by themselves (self-stigma). Confirmation by HTLV infection causes social withdrawal (and self-isolation). This withdrawal happens with people in family, institutional and social life. This experience reaffirms itself in the face of the possibility of new demands arising from physical dependence secondary to infection and illness by HTLV.[11]

From the speech, it is inferred that there is no social reclusion while people are asymptomatic and physically well. The individual manages to achieve socially planned goals, and both family and friends feel benefited. The loss of work capacity and the decrease in a financial condition also contribute to the removal of people who expect from those with whom they relate that they are well and can also enjoy a satisfactory condition. When these expectations are not met, "friends" and family members are discredited and alienated. For all that, people tend to stay away from those who have HTLV.[12-13]

In summary, people considered healthy have a conception that having HTLV gives a sense of being "different" or "limited," which makes the subject labeled, excluding them from social interactions, considered mostly simple but essential for the person's well-being.

The third speech expresses fear, sadness, suffering, and loss of life; resulting from illness and its consequences. Upon discovering that the progression of the infection is resulting in chronic disease, it is necessary to start the process of awareness and acceptance of this disease. In this course, several feelings are entangled, especially if the affection is sexually transmitted and surrounded by prejudice, as in the case of HTLV.

The burden and extension of the disease cause frustration and interfere in the patient's life, reverberating through feelings of worthlessness, devaluation, depression, and being a burden.[11]

Because of the physical limitations resulting from the disease, women become dependent on other people, bringing significant changes that affect their self-image and daily lives. These changes make countless feelings unfold, such as shock, disappointment, and low self-esteem that lead people affected by HTLV to depressive behavior.[3] In speech 3, the loss of self-esteem, the desire to talk is noticeable. The person prefers to live in isolation, finally losing the will to live.

Getting sick is seen as a threat to life, and the intensity of its repercussions depends on the characteristics of the pathology and the person himself. The presence of HTLV causes different reactions, mainly in the psychosocial aspects, emphasizing "dismay, hopelessness, disbelief, anxiety, as the main changes perceived".[3] Losses can gain large proportions and reach various spheres that compromise personal, affective, social, spiritual, and professional life.

The progression of HAM/TSP (tropical spastic paraparesis/HTLV-1 associated myelopathy) brings out feelings of fear for the uncertainty of the future and dependence on other people, feelings of worthlessness, failure, frustration, sadness, and hopelessness. In addition, this disease generates anxiety, depression, irritability, and aggressiveness, both because of the possibility and the real presence of loss of motor capacity.[14]

Thus, it can be inferred that a stimulating factor of stress and consequently of other feelings in women affected by HTLV is the need to be present at the treatment clinic periodically, forcing them to miss work (when the virus symptoms allow the same to work) which is not always tolerated by the superior. They need to leave their children with other people, in addition to the demands, often from their partners and family members, regarding the performance of their socially delegated tasks, which they do not perform to go to treatment. Thus, the displacement itself is stressful since the vast majority need to leave the city where they live. All these facts culminate in physical and emotional fatigue, making the person feel useless and lacking confidence, as reported in speech 3.

The feeling of uselessness is also intrinsic to women affected by HTLV, constituting a potentially triggering situation for different feelings, many of them related to suffering since the limitations caused by the disease make it difficult or impossible to perform previously considered tasks be simple execution.[4] This assertion is proven in the following fragment of the speech *"we feel very useless [...]. Do you know the value of my life that many gave me? Zero. I also gave myself zero"*.

Often, uselessness is physical restriction and includes the limitation or loss of decision-making concerning one's own life.[14] This situation can reinforce the feeling of terminality in the process of living, as expressed in the report: "after I got in a wheelchair, I've tried to commit suicide three times." Emotional repercussions of the HTLV diagnosis can lead to depression and consequently to suicidal ideas.[5]

The diagnosis of an STD, for most women, results in negative aspects, especially in the case of an unknown disease such as HTLV. It is essential to awaken a new look at the patient with HTLV, considering the pathophysiological aspects of the disease and the psychosocial issues that intertwine this person's life.

Finally, in the fourth speech, it is clear how religion and the family, essentially the children, are identified to strengthen the weaknesses that the HTLV imposes and the new path necessary for the life of the woman affected by the virus. Some people seek religion and family support predominantly to alleviate the impact of the disease.[15]

The chronic disease, by itself, puts the person in an uncomfortable situation.[3] It is understood, therefore, that when it comes to the discovery of HTLV seropositivity, there is a more intense disruption in the person's daily life - an unknown disease, with an uncertain prognosis, and that, as it can be sexually transmitted, it is surrounded by prejudice and stigma regarding the person's moral behavior. However, affected women can create encouragement to deal with the adversities brought abruptly by this disease.

The approach to the patient with HTLV, and exceptionally the one with HAM/TSP, is extremely relevant to family/social support, given the physical and emotional dependence that these patients establish in the process of falling ill and during the maintenance of life, being a determining factor for the course of the disease.[15] It is important, above all, to recognize that there is a lot to be done for families facing the chronic condition.[14]

As seen in the speech, even though it is a progressive and disabling disease, the idea of having people who care about their well-being drives those affected to look for ways to delay or minimize these events, as shown in the excerpt: *"I just plan to have one, fight for life! After all, my only joy is "my children," such wonderful people who encourage me, special, trustworthy people."*

It is also understood from the speech that the experience of religiosity also has a stimulating role in the lives of women, who see God from a perspective of a provider of their strength, making them bear and overcome difficulties, as revealed in the speech: *"If God isn't in control, we don't have the strength to bear it. And that's where I invest my strength"*.

Thus, faith has played an important role in people's lives, making the individual believe in a supernatural provision, capable of intervening favorably in their concrete life situation, in the course of the disease and in its effects on daily life, through which the relief of suffering happens, of the despair that settles in the life of those who get sick.[16] The relationship with the divine is idealized not only as a way of coping but also as a hope of a cure, even if the disease is incurable, as expressed in this segment: *"even if the doctors say that there is no cure, faith is in Jesus who is the physician of doctors, I believe I will be healed in the name of Jesus"*; It is possible to find in religion an encouragement in the face of the statements present in the medical discourse, that there is no cure.[16]

Thus, it is understood that the means of coping with the illness caused by HTLV are essential, as it is an incurable and progressive disease that can lead to significant injuries such as plegia of the lower limbs, contributing to minimizing the effects and improving the quality of life.[3] It should be noted that drug therapy is not an exclusive way of treating a chronic disease but also attitudes that seek the person's well-being, such as measures of comfort, affection, and support from important people.

Therefore, it is crucial to have a more refined and more welcoming look at the ways that the person describes as an aid in coping with the disease, among which are religiosity and the family, as they are resources for reinterpreting life, welcoming the anxieties, helping them in the search for autonomy.

The study has some limitations, as it was not possible to include women from other services that aid people living with the HTLV and other regions of the country. Furthermore, it was not possible to work with strategies to intervene in fighting stigma, improving self-esteem and self-care of the participants.

Conclusion

HTLV seropositive women experience stigma from their families, partners, and society, which is associated with the fact that it is a sexually transmitted disease, marking them as endowed with socially inappropriate behaviors and attitudes. However, these discriminatory actions can be take place because of the lack of knowledge about the disease.

Faced with this situation, several women resort to strategies to circumvent stigma, hiding details related to HTLV infection, or even covering up their serological condition completely, even from their family members.

On the other hand, women affected by HTLV recognize the importance of family support and religion to face the infection/illness. Thus, the health care provided to women living with HTLV should not be based only on physical well-being but also on biopsychosocial well-being, thus contributing to the confrontation of stigma in the daily lives of HIV-positive women.

It should be noted that respect for the exercise of autonomy of seropositive women is essential. After all, this infection can cause multiple losses and limitations. However, it does not mean abolishing the power of decision over themselves from their lives.

Finally, it is noteworthy that the results of this study will bring relevant information to nursing, as a profession that cares, and to health professionals in general, about the impact that HTLV can have on the lives of women affected by this virus, thus contributing to the promotion of holistic care, which preserves their autonomy and biopsychosocial experience.

Author contributions

All authors participated in all stages of the study, writing and reviewing the report.

Conflicts of interest

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

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