

HTLV: a stigmatizing infection?

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Ionara Ferreira da Silva Garcia ¹
Élida Azevedo Hennington ²

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Abstract

HTLV is a virus that affects human T-cells. Brazil is the country of the world with the largest absolute number of HTLV cases. Estimates by the Ministry of Health point to 700,000 to 2 million infected Brazilians. The majority are asymptomatic carriers, but some persons may develop degenerative neurological conditions such as tropical spastic paraparesis, in addition to leukemia and lymphoma. The forms of transmission and clinical manifestations such as progressive motor incapacity, genitourinary disorders, in addition to restriction of maternal breastfeeding, impact daily life and can lead to social discrimination and stigma. The stigma denotes violation of social norms and reinforces prejudice and inequalities. This article aims to discuss the concept of stigma and its repercussions on persons living with HTLV. The discussion is based on a literature review on the theme and the authors' experience with care for persons affected by the infection and illness. The study found that both HTLV carrier status and HTLV-related illness can be stigmatizing for individuals, who feel inferior for being infected with a potentially serious and even fatal disease, although incompletely understood and loaded with derogatory stereotypes. This situation can have negative repercussions on access to health services, treatment adherence, and pursuit of rights. Public policies should help mitigate such stigmatization, ensuring the rights of individuals in a situation of vulnerability due to HTLV in order from them to live as protagonists in the exercise of their civil rights.

HTLV; Social Stigma; Prejudice; Community Participation

Correspondence

I. F. S. Garcia
Instituto Nacional de Infectologia Evandro Chagas, Fundação
Oswaldo Cruz.
Av. Brasil 4365, Rio de Janeiro, RJ 21040-900, Brasil.
ionara.silva@ini.fiocruz.br

¹ Instituto Nacional de Infectologia Evandro Chagas, Fundação
Oswaldo Cruz, Rio de Janeiro, Brasil.

² Escola Nacional de Saúde Pública Sergio Arouca, Fundação
Oswaldo Cruz, Rio de Janeiro, Brasil.



Introduction

In 1980, HTLV-1 was identified as the first retrovirus associated with cancer in humans ¹, described as human T-cell lymphotropic virus type 1, isolated from a patient with malignant T-cell neoplasia. In 1982, HTLV-2 was isolated, a virus rarely associated with any disease, and in 2005 HTLV-3 and HTLV-4 were isolated from individuals in Africa ², but they have not been associated with any disease to date.

Most HTLV-1 carriers are asymptomatic. An estimated 5% of persons infected with HTLV-1 develop health problems related to the virus. In these cases, the infection can evolve to severe degenerative neurological conditions and other manifestations, even fatal, such as leukemias and lymphomas, generally 40 to 60 years post-infection ¹. According to Gonçalves et al. ³, the World Health Organization (WHO) recognizes HTLV-1 as the etiological agent of adult T-cell leukemia (ATL). Besides ATL, other disease conditions associated with HTLV-1 infection include neurological manifestations such as tropical spastic paraparesis/HTLV-1-associated myelopathy (TSP/HAM) with progressive decrease in lower limb strength, urinary incontinence, and repeated urinary infections, hematological manifestations like adult T-cell leukemia/lymphoma (ATLL), ophthalmological manifestations like HTLV-1-associated uveitis (HAU), cutaneous manifestations like HTLV-associated infective dermatitis (HAID), and psychiatric disorders, among others. There is still no cure for the infection.

Just as HIV (human immunodeficiency virus) and HCV (hepatitis C virus), HTLV-1 has horizontal and vertical transmission routes. Horizontal transmission occurs by the sexual route (unprotected sexual relations) and bloodborne route (blood transfusions, sharing syringes and needles, organ transplants, exposure to contaminated blood or blood products). Vertical transmission occurs from mother to child during pregnancy and breastfeeding. In endemic areas, the vertical transmission plays the principal role in the transmission chain, especially via breastfeeding ⁴.

Brazil is the country of the world with the largest absolute number of HTLV cases ⁵. Estimates by the Brazilian Ministry of Health indicate 700,000 to 2 million infected Brazilians ⁶. There is no specific national policy for HTLV, but the virus is among the infectious agents tested in the material collected in blood centers throughout the country since 1993 ^{7,8}. It has thus been possible to identify infected donors and prevent transmission of the virus through blood or blood product transfusions. However, this sexually transmissible infection (STI) is still not part of the list of diseases of compulsory notification in Brazil ⁹, and serology for the virus is not part of the protocol for prenatal care recommended by the Ministry of Health ¹⁰.

Although invisible to society, still not acknowledged as a priority in public policies and unfamiliar even to many health professionals, HTLV infection can become a stigma for those living with the virus, marking and accompanying them throughout life.

This article aims to reflect on the concept of stigma and its relationship to HTLV based on authors like Goffman, Parker, and others, a literature review on the theme, and the authors' experience in care for persons with the infection and illness in a public health institution specializing in infectious diseases. The discussion on stigma and HTLV allows a deeper understanding of certain attitudes and behaviors by persons living with the virus and their strategies for coping with an incurable infection and that can evolve to severe, debilitating, and incapacitating clinical manifestations and cause significant repercussions on the persons' lives. The article also aims to give visibility to the theme and foster care and treatment by health services for these persons in their situation of vulnerability.

The methodological trajectory

A literature review was conducted in July-August 2018 on the theme of HTLV and stigma. The search was done by cross-referencing the descriptors "stigma" and "HTLV", using the operators "and HIV" and "and not HIV" in PubMed, LILACS, SciELO, and Google Scholar. The search only included open-access publications in Portuguese, English, and Spanish, and there was no limitation on year of publication. The search located two articles in PubMed, two articles in LILACS, and none in SciELO. In Google Scholar, 654 publications were identified. After reading the titles and abstracts, publications were excluded that did not refer to HTLV, those whose subject was HIV/HTLV-3, in which HTLV only

appeared in the bibliographic references, and in which stigma was treated as a botanical or zoological term. In this first stage, we excluded the majority of the publications because they did not fit our object of study, and only 20 studies were retrieved. After excluding duplicates, 18 publications were analyzed, and after reading the material, eight publications were discarded, two because they were not available as full text, five because they did not present a direct relationship between HTLV and stigma, and one because it did not explain the research methodology. Thus, this study considered 10 publications (Box 1).

Box 1

Selected publications on HTLV and stigma, in chronological order.

Title	Authors (type and year of publication)	Overall objective	Method	Research subjects	Study site
<i>Awareness of Mother-to-Child Transmission of Human T-Cell Lymphotropic Virus (HTLV) Type I through Breastfeeding in a Small Group of HTLV-positive Women in Maripasoula and Papaïchton, French Guiana</i> ³⁵	Oni T, Djossou F, Joubert M, Heraud JM (article/2006)	Assess awareness of HTLV transmission via breastfeeding in a group of women and examine policies to reduce transmission	Data collected in January-February 2004 with an interview using a questionnaire and home visits	Group of 40 women under 55 years of age with HTLV	Household and medical units in Maripasoula, an isolated village in southwestern French Guiana
<i>Convivendo com o HTLV-1</i> ³³	Orge G, Travassos MJ, Bonfim T (article/2009)	Understand how individuals infected with HTLV-1 perceive the infection and its consequences	Semi-structured interviews from November 2001 to June 2002, with thematic analysis	Group of 57 infected individuals	Patients from the Multidisciplinary HTLV Outpatient Clinic (HUPES/UFBA); Salvador, Bahia State, Brazil
<i>Disfunção Erétil em Pacientes Infectados pelo HTLV-1</i> ³⁹	Oliveira P, Castro NM, Tannus M, Machado C, Carvalho EC (article/2009)	Determine prevalence of erectile dysfunction in patients with HTLV-1 and its association with symptoms of hyperactive bladder	Cross-sectional study of HTLV-1-positive patients (by ELISA and Western blot)	111 men	Patients from the Multidisciplinary HTLV Outpatient Clinic (HUPES/UFBA); Salvador, Bahia State, Brazil, from October 2003 to December 2006
<i>Impacto da Mielopatia Associada ao HTLV/ Paraparesia Espástica Tropical (TSP/HAM) nas Atividades de Vida Diária (AVD) em Pacientes Infectados pelo HTLV-1</i> ⁴¹	Coutinho IJ, Castro Filho BG, Lima J, Castello C, Eiter D, Grassi MFR (article/2011)	Describe performance in activities of daily living in patients infected with HTLV-1 with TSP/HAM and measure impact of the disease on quality of life	Cross-sectional descriptive study using <i>Health Assessment Questionnaire</i> and <i>Short-Form Health Survey</i>	73 patients with TSP/HAM	Patients treated at the HTLV Center of the Bahian School of Medicine and Public Health; Salvador, Bahia State, Brazil
<i>Living Invisible: HTLV-1-Infected Persons and the Lack of Care in Public Health</i> ³⁷	Zihlmann KF, Alvarenga AT, Casseb J (article/2012)	Understand how women and men with HTLV-1 experience the disease and which problems exist in their health processes	Qualitative study with participant observation and interviews	Group of 13 symptomatic and asymptomatic patients	Outpatient Clinic, Institute of Infectious Diseases Emilio Ribas; São Paulo, Brazil

(continues)

Box 1 (continued)

Title	Authors (type and year of publication)	Overall objective	Method	Research subjects	Study site
<i>Vivência da Sexualidade: Representações Sociais de Pessoas Soropositivas para o HTLV</i> ³²	Rivemales MCC (doctoral dissertation/2013)	Understand the meaning of sexuality for men and women with HTLV	Quantitative and qualitative study	74 persons of both sexes with HTLV	Outpatient Clinic, Department of Infectious Diseases (HUPES/UFBA); Salvador, Bahia State, Brazil
<i>Metaanálisis sobre Calidad de Vida Relacionada con la Salud de Enfermedades Infecciosas, 2002-2013</i> ³⁸	Alzate CAV, Higuaita-Gutiérrez LF, Cardona-Arias JA (article/2014)	Compare quality of life and infectious diseases from the WHO perspective	Systematic review with meta-analysis of databases	Analysis of published studies	Analysis of 14 studies that applied the WHO quality of life scale in 2013
<i>Vivência Sexual e Afetiva de Mulheres com Incontinência Urinária Secundária ao HTLV</i> ⁴⁰	Paranhos RFB, Paiva MS, Carvalho ESS (article/2016)	Understand sexuality of women with urinary incontinence secondary to HTLV	Qualitative study. In-depth interviews. Content analysis	10 women	Outpatient Clinic, Department of Infectious Diseases (HUPES/UFBA); Salvador, Bahia State, Brazil
<i>Qualidade de Vida e Depressão em Pessoas Vivendo com HTLV-1</i> ³⁶	Reuter L (masters thesis/2016)	Assess correlation between depression and quality of life in persons with HTLV-1	Cross-sectional study from June 2014 to July 2016, using standardized WHO questionnaires	91 asymptomatic carriers, 54 patients with TSP/HAM and 26 uninfected	HTLV Center of the Bahian School of Medicine and Public Health; Salvador, Bahia State, Brazil
<i>Sentimentos de Mulheres Soropositivas Acerca da Não Amamentação</i> ³⁴	Teixeira MA, Paiva MS, Couto PLS, Oliveira JF, Wolter RMCP (article/2017)	Understand feelings of HIV/HTLV seropositive women on not breastfeeding	Qualitative study, use of interactive descriptive and dynamic survey	134 women	Patients treated at Referral Centers for STI/AIDS and HTLV; Salvador, Bahia State, Brazil

HUPES/UFBA: Professor Edgard Santos University Hospital/Federal University of Bahia; STI: sexually transmitted infections; TSP/HAM: tropical spastic paraparesis/HTLV-1-associated myelopathy; WHO: World Health Organization.

Source: prepared by the authors.

The studies selected in the literature review are not dedicated exclusively to the discussion of HTLV and stigma, but they refer to stigma as one of the elements faced by the groups. Box 1 shows a synthesis of the selected studies, and Box 2 presents the main themes identified and the contents discussed. In the studies, we identified seven main themes related to stigma: sexuality, vertical transmission, subjectivity, social isolation, physical incapacity, mental health, and the infection's invisibility.

Stigma as a social construct

Erving Goffman ¹¹ was a pioneer in the theoretical discussion on stigma, publishing the first studies in the 1960s. According to the author, stigma is defined as a scar, a shameful sign, and relates to a negative attribute, profoundly depreciative, or a deteriorated identity. It is shaped from the incongruency between the stereotype of what is purportedly "perfect" or "normal" and attributes differing from this norm imposed by society, in a language of relations and not of attributes per se.

Box 2

Principal themes and contents identified in selected publications on HTLV and stigma.

Themes	Publications	Contents
Sexuality	Rivemales ³² (2013); Reuter ³⁶ (2016); Coutinho et al. ⁴¹ (2011); Orge et al. ³³ (2009); Paranhos et al. ⁴⁰ (2016)	Moral judgment of sexually transmitted disease and feelings of shame and guilt; association of HTLV with HIV
Vertical transmission	Teixeira et al. ³⁴ (2017)	Act of not breastfeeding in relation to diagnosis of the infection and secrecy; feelings of sadness and guilt
	Reuter ³⁶ (2016); Oni et al. ³⁵ (2006)	Social stigma due to vertical transmission
Subjectivity	Orge et al. ³³ (2009)	Self-judgment, guilt, and shame; the disease as punishment and as metaphor
	Rivemales ³² (2013)	Self-stigma and self-judgment
Social isolation	Rivemales ³² (2013); Coutinho et al. ⁴¹ (2011); Zihlmann et al. ³⁷ (2012); Reuter ³⁶ (2016); Paranhos et al. ⁴⁰ (2016)	Silencing and cover-up; hiding the diagnosis; social exclusion and social death
Physical incapacity	Alzate et al. ³⁸ (2014); Oliveira et al. ³⁹ (2009); Paranhos et al. ⁴⁰ (2016); Coutinho et al. ⁴¹ (2011)	Limitations due to development of the disease and stigma from sequelae and clinical manifestations
Mental health	Reuter ³⁶ (2016)	Depression and quality of life
Invisibility of the infection	Oni et al. ³⁵ (2006); Rivemales ³² (2013); Zihlmann et al. ³⁷ (2012); Santos et al. ⁴² (2017)	Lack of knowledge about HTLV among the general population and health professionals

Source: prepared by the authors.

The approach to stigma has changed over time. While Goffman focused on the individual and interpersonal level when discussing the phenomenon, a second wave of authors emerged and new readings addressed the theme, especially with the advent of HIV/AIDS and the perspective of human rights and health. These authors deal with stigma and its synergies and other implications such as discrimination and prejudice as structuring processes in inequalities on grounds of class, race/ethnicity, gender, sexuality, territory, and religion ^{12,13,14,15,16,17,18}.

An element that accompanies stigma is prejudice. Both stigma and prejudice refer to negative attributes assigned by some to others who fail to “fit” socially established norms, the result of an initial feeling of uncanniness that leads to a series of negative and equivocal perceptions. The concept of stigma has been used more to refer to illnesses, disabilities, or what are considered deviant behaviors, while prejudice refers more to ethnicity and race. The two bear similarities when they describe situations of exploitation, domination, and affirmation of the social norm ^{13,14}.

The same attribute that stigmatizes someone confers normality to another. “Normal” individuals elaborate an ideology to explain the inferiority of certain persons using stereotypes that translate the person as a whole, e.g., “crackhead”, “pothead”, “AIDS victim”, “cripple”, “leper”, “loony”, and “faggot”, among other pejorative terms. According to Godoi & Garrafa ¹⁹, there is a dehumanization of the stigmatized individual, whose identity is thenceforth defined by the stigma itself. According to Link & Phelan ²⁰, stigma implies a kind of social information that transmits signs or labels to call attention to a degrading identity that differs from the socially accepted norm.

For Parker & Aggleton ²¹, stigma is influenced by the social context, and understanding it is fundamental for developing actions to fight it and reduce its effects. The authors also emphasize that stigma reinforces social and structural inequalities, in addition to accentuating differences between “normal” and “abnormal” individuals. According to the authors, stigma turns difference into inequality and is employed by social actors who defend their hierarchical position of domination.

Stigmatization is a social process that produces discourses, habits, and structures that sustain it, and discrimination is a process that materializes power relations, particularly on grounds of gender, sexuality, class, and race. In this sense, stigma accentuates labeling, categorization, and social rejection. The reasons for societies to stigmatize certain groups may vary, but they are generally based

on relations of domination and social control. Thus, stigma is used to produce and reproduce social inequality and maintain the social order ¹³.

Several studies show that stigma can negatively affect individuals' living conditions and health, such as decreased self-esteem, loss of identity, and despair ²², withdrawal and rejection of professional care ²³, and difficulty in access to (and use of) services ²⁴.

Felicissimo et al. ²⁵, based on a literature review on the relationship between internalized stigma and self-esteem, argue that internalization of stigma can lead to serious harmful effects, and that individuals may anticipate their devaluation and discrimination, even when these have actually not occurred. The authors also indicate that internalization of stigma leads to decreased self-esteem with lasting effects, and that it deteriorates social relations, fuels social withdrawal, and discourages the search for specialized care. Stigma may thus be one reason for non-adherence to health treatment.

According to Corrigan et al. ²⁶, there is both public stigma and self-stigma. Public stigma is society's perception of a given individual whose characteristics differ from socially accepted norms. Internalized stigma or self-stigma occurs when the individual appropriates and identifies with his or her stigmatized position. The internalization of stigma leads to decreased self-esteem and feelings of worthlessness, shame, guilt, and self-reproach ²⁶.

According to Goffman ¹¹, individuals that society views as abnormal, different, marginalized, or inferior due to what it views as physical, psychological, or character flaws have to struggle constantly to build a social identity. The author refers to the control of information that stigmatized persons attempt to exert concerning themselves and describes them as discredited and discreditable, signaling strategies that stigmatized individuals use to deal with rejection by others and the complexity of information they project on others. Discredited individuals have characteristics that are visibly discrepant from those of "normal" individuals. Meanwhile, a discreditable individual also has distinct characteristics, but they are not always immediately known to or perceived by others. In this case there is a manipulation of information, covering or disguising a defect in order for the stigmatizing trait to remain less perceptible.

HIV/AIDS as the reference in discussion of stigma

Much discussion has focused on stigma related to mental disorders, and with the AIDS epidemic starting in the 1980s, discussion also turned to stigma related to the virus and its consequences ¹². Richard Parker, one of the main authors discussing stigma and its repercussions on HIV and AIDS, proposed to take a step beyond Goffman's concept defining stigma as a mark. Parker ^{14,21} problematized stigma as a social process related to issues such as power, domination, and social inequalities. The author acknowledges that in recent years, studies on stigma and prejudice, conceptualized as similar movements, have contributed to the understanding of health consequences for subjects in this scenario ¹⁴. Especially in relation to HIV, Parker endeavored to understand how some subjects and groups come to be socially excluded, and which forces reinforce this process.

Parker & Aggleton ²¹ contend that HIV and AIDS-related stigma does not operate exclusively on the disease itself, but also on preexisting forms of stigmatization and exclusion. They reiterate that the AIDS epidemic reinforced the stigma of groups already stigmatized based on what were viewed as their deviant behaviors, such as homosexuals, drug users, and sex workers. The authors cite Jonathan Man in his address to the United Nations General Assembly in 1987, speaking on the three AIDS epidemics: the first was the silent worldwide spread of the virus; the second was the AIDS disease itself; and the third was the social reaction with stigma, discrimination, and denial.

The issue of HIV/AIDS-related stigma is still a global problem, despite strides in drug therapy, allowing effective treatments and survival for persons with HIV. The authors admit that, thus far, the "complexity of the virus" has prevented the discovery of drugs that can lead to cure, but they highlight that the "complexity of social forces" involved in the production and reproduction of HIV/AIDS-related stigma is far greater ²¹. They argue that progress in the struggle against HIV/AIDS-related stigma will only be possible by developing actions for social mobilization to resist these processes of prejudice and discrimination.

Monteiro & Villela¹⁶ organized an important anthology on the theme of discrimination, stigma, and AIDS. The authors emphasize that the Brazilian research output on stigma and AIDS is still limited, with a predominance of studies on stigma based on Goffman's notion of an individual mark rather than associating stigma with social processes in the production of inequalities. They highlight that stigma negatively affects living conditions and access to health, accentuating the vulnerability of groups historically discriminated on the basis of gender, race, color, social diversity, and certain diseases. They problematize the importance of understanding stigma and HIV/AIDS related to the concept of structural violence proposed by Parker¹².

Monteiro et al.¹⁷ underscore that despite advances in drug therapy and social mobilization to confront the disease through the creation of nongovernmental organizations, AIDS-related stigma and discrimination still exist, backed by negative moral stereotypes. Villela & Monteiro¹⁸ also discuss stigma when reflecting on prostitution, abortion, and HIV in women. They state that stigma and HIV reflect the link between historically discriminated persons like homosexuals, prostitutes, and drug users and preestablished social norms. They call attention to the invisibility and gender inequality by which "feminization" of the epidemic only become the object of concern when it was found that the epidemic was increasing in non-prostitute women, reinforcing the stigma on persons who exchange sex for money. They also point out that AIDS-related stigma involves structural changes and cultural interventions.

The study by Brown et al.²⁷ on an intervention to reduce stigma from HIV/AIDS cites the negative association between AIDS stigma and socially marginalized groups and underlines that stigma negatively affects preventive behaviors like the search for diagnosis and treatment.

When a moral meaning is assigned to a given disease, it is re-signified, and according to Sontag²⁸, the disease becomes metaphor. The author investigated the meanings assigned to certain diseases, especially cancer and AIDS, in order to demystify the guilt attributed to the affected individuals. These metaphors exacerbate the suffering of the person, who must cope not only with the pain from the disease, but also the stigma's emotional pain.

Zucchi et al.²⁹ analyze the literature on HIV/AIDS-related stigma and discrimination in Brazil and conclude that the studies do not propose to mitigate stigma and discrimination, but suggest actions focused on prevention (condom use, access to comprehensive healthcare) or refers to AIDS illness (stigmatization and violation of sexual and reproductive rights, isolation, and mental distress). The authors signal that no studies were found on psychosocial or psychoeducational interventions to reduce stigma in the first decade of the epidemic, despite organizations for social mobilization in solidarity with HIV-seropositive individuals, as reported by Parker¹⁵, Berkman et al.³⁰, and Galvão³¹. Most of the interventions cited in the international literature are concerned with strategies to increase tolerance in contact with persons living with HIV/AIDS.

What the literature on stigma and HTLV says

The theme of stigma and HTLV has received little attention thus far in the Brazilian and international literature. This may be due partly to the restriction on the use of the descriptors HTLV and stigma in our search, the lack of recognition of this STI as a neglected disease, distribution of the virus in some endemic regions in Sub-Saharan Africa, Japan, South America, Central America and the Caribbean, and Asia, and the higher prevalence in specific populations (blacks, Asians, and indigenous people)⁵.

Of the total of 10 selected studies, we highlight three publications that discuss the stigma experienced by the groups studied: the thesis by Maria Rivemales on sexuality in men and women with HTLV, with a chapter dedicated to the stigma associated with the infection³²; the article by Orge et al.³³, which refers to the subjective issue of HTLV infection and lists the most recurrent elements associated with stigma, including discrimination, guilt, and shame; and the article by Teixeira et al.³⁴ that discusses the feelings of women coinfecting with HIV and HTLV concerning not breastfeeding, providing important insights on the stigma experienced by these women.

Rivemales³², analyzing experiences with HTLV-related stigma, states that persons with HTLV experience and suffer stigma, whether from family members, sexual partners, friends, or themselves (self-stigma). She argues on the moral weight attached to sexually transmissible diseases, embarrass-

ment for the infected person, and connotations of deviant behavior that deprecates the person with the infection. The author underscores the judgment that stigmatized persons make of themselves and the semantic similarity between HTLV and HIV, potentially leading to confusion for those whose seropositive status is disclosed. She also refers to infected persons' feelings towards disapproval by others in relation to the affective-sexual experience prior to the infection; to the moral judgment of being labeled as promiscuous; and to feeling hurt, ashamed, and guilty for having contracted HTLV.

Rivemales mentions silencing of one's serological status as an alternative for persons living with HTLV to protect themselves from others' gaze and judgement, while confirming one's status of normality in relation to persons around them. Symptomatic carriers are subject to public scrutiny, evaluation, and judgement of their health condition. Fear of possible social exclusion due to serological status often leads patients to disguise the infection or to speak of another diagnosis, omitting the HTLV. The author emphasizes that covering up or hiding one's serological status results from fear of prejudice and discrimination and is also a strategy to protect against publicizing a negative image. Patients in this situation have a negative self-assessment, anticipating the kind of assessment and judgement from the public gaze. The author points to social withdrawal as another strategy used to cope with the stigma, hiding signs and symptoms in order to avoid stigmatizing situations. Finally, she refers to the social death experienced by HTLV carriers who face the loss of love and affection from family and friends ³².

Orge et al. ³³ identify as recurrent themes in the discourse of HTLV-infected patients: fear of the disease as punishment, discrimination, and feelings of sadness, guilt, and rage. They underline the meanings assigned socially to a given disease and the personal significance assigned to it by the infected person. They refer to some diseases as metaphors, linked to symbolisms. In this case, even without having suffered discriminatory acts, the carrier may feel stigmatized due to the stereotypes concerning the disease itself, the sexual transmission route, or the association with HIV.

Teixeira et al. ³⁴ analyzes the feelings of women coinfecting with HIV and HTLV about not breastfeeding, signaling conflicts and feelings of sadness, fear, rage, and guilt towards the situation, permeated by the symbolic representation of breastfeeding as a relationship of love between mother and child and also the information spread by the media about breastmilk as the ideal food for the infant. The authors underline the importance of clarification on the transmission of diseases by breastfeeding by infected mothers and the possibility of prevention. Oni et al. ³⁵, in a study on vertical transmission of HTLV via breastfeeding in French Guiana, conclude that ignorance towards the virus increased the stigmatization of infected persons, even more than with HIV.

Given the stigma of seropositive status, many women hide the diagnosis, and when they fail to breastfeed, they are forced to create situations or socially accepted excuses to justify not breastfeeding, suffering twice: for not breastfeeding and from the condemnation of their seropositive status. Social pressure for breastfeeding leads to embarrassing situations for seropositive women. In addition to the pain of not breastfeeding, these mothers suffer a "social punishment".

Another relevant study is the dissertation by Lilian Reuter ³⁶, assessing the presence of depressive disorder and quality of life in persons with HTLV, a pioneering study since depression in relation to HTLV has received little attention. The impact of the diagnosis of a chronic, slow, and progressive disease, even in asymptomatic patients can lead the individual to present anguish, fear, altered mood, depression, anxiety, revolt, sadness, and other changes in quality of life. The psychosocial problems not only involve difficulty in establishing and maintaining relationships and fear or guilt in relation to pregnancy, but can also precipitate disturbing emotional reactions in individuals, contributing to isolation and less participation in social life.

Zihlmann et al. ³⁷ seek to understand how women and men living with HTLV-1 experience the disease and which problems exist in their health processes. They report that misinformation in society and among health professionals concerning the disease and the stigma of diagnosis favor invisibility of the infection and continuity in the transmission chain.

Four publication report on stigma vis-à-vis the physical incapacity developed as a result of HTLV. Alzate et al. ³⁸ conduct a systematic review on quality of life in infectious diseases and cite HTLV as an indirect factor for stigma due to the physical incapacity that some individuals develop, generating sadness, guilt, shame, and fear of interaction with others. Oliveira et al. ³⁹, in a study on erectile dysfunction and hyperactive bladder in patients with TSP/HAM, list factors that can influence patients'

erectile function, such as functional limitation, reduced self-esteem due to the stigma of myelopathy, and fear of transmitting the disease to uninfected partners, among others. Paranhos et al.⁴⁰ present the issue of sexuality for women with urinary incontinence secondary to HTLV. They state that sexuality involves social and cultural aspects, beliefs, and ideologies and is influenced by prejudice, stigma, physical changes, and fear of transmission. They suggest that low self-esteem caused by the disease jeopardizes sexual interest, hinders new relationships, and favors social withdrawal. Coutinho et al.⁴¹ describe the impact of HTLV-associated myelopathy on patients' quality of life, emphasizing the chronic pain associated with anxiety and depression, and indicate that the infection bears the stigma of a sexually transmitted disease.

HTLV: the patient, the disease, and the stigma

Stigma is not an individual property, but a social construct, varying from society to society according to the cultural and historical context. Since culture changes along with social changes, a given stigma also undergoes changes¹¹. For example, individuals with leprosy have borne a heavy stigma in society since ancient times. Called "leper", a person with Hansen's disease was supposed to be shunned from the social community and confined to leper colonies or leprosaria. However, with the discovery of the form of transmission, medicines, and the possibility of treatment and cure, the stigma borne by persons affected by leprosy gradually lost its weight. Another example is paraplegia: it may be the target of stigma in many societies, but as the rights of persons with disability were gained over time, the force of this stigma also waned.

Santos et al.⁴², on illness and limitations from HTLV, underscore the ignorance towards this disease in the general population and even among health professionals. They problematize symptomatic patients' journey in search of diagnosis and follow-up due to ignorance and the invisibility of the virus. Rivemales³², Oni et al.³⁵, and Zihlmann et al.³⁷ also point to the infection's invisibility.

In the case of HTLV-positive individuals, symptomatic patients may omit the principal diagnosis. Many patients in treatment request secrecy in relation to their diagnosis, explaining that they feel inferior, victims of prejudices and judgments by family members and their network of relations due to an illness that carries a "burden" of stereotypes related to bad behavior or moral maladjustment. Initially, it seems difficult to talk about HTLV with family and friends, even more than talking about or explaining what HIV is, for example. In addition to the lack of knowledge in a large share of society on the virus, forms of transmission, and associated diseases, there are subjective or personal issues that are difficult to approach. Some persons living with the virus prefer to disclose secondary diseases, with TSP/HAM and LLTA as options for responses by some patients when asked about their diagnosis. The request to health professionals for total or partial secrecy concerning their HTLV status ratifies the stigma related to the disease.

The discussion by Goffman¹¹ on categories of discredited or discreditable individuals and the manipulation of information could refer to the behavior of patients living with HTLV who ask for secrecy concerning the principal diagnosis, as we observed during care for these patients. It seems to be more difficult to explain living with HTLV than to present oneself as a person with disability or to disclose that one has a serious disease such as leukemia, for example. Situations like these, witnessed in our professional experience, motivated us to reflect on HTLV and stigma and the repercussions on treatment adherence in the daily lives of persons living with the infection.

For Goffman¹¹ and Parker & Aggleton²¹, stigmatization is socially produced, shaped by the social and situational context from the perspective of the stigmatizer, the stigmatized, and the interaction between the two. HTLV, like HIV, carries stigma and prejudice, indicating supposedly morally marginal individuals, who may be suffering divine punishment or experiencing an unwanted situation due to their own acts, as stated by Orge et al.³³ and Teixeira et al.³⁴. As with HIV, HTLV-seropositive individuals may face embarrassment if they need to explain the virus when they develop signs and symptoms or have their diagnosis revealed. Persons with the infection tend to ask themselves, "Why me?" or "Why with me?" or say ironically, "I was chosen", and end up suffering twice: in addition to the diagnosis itself, they suffer the guilt of contamination and the possibility of transmitting the virus to their partner, besides being part of a small portion of seropositive individuals who develop the ill-

ness. Another important issue is the unhappiness or guilt, feelings that many women carry for having transmitted the virus to their children; likewise, children may have these same feelings towards the mother who transmitted the virus to them ³⁴.

According to Parker & Aggleton ²¹, many stigmatized individuals avoid social contact or hide the cause of embarrassment, such as from diagnosis of an infectious disease, homosexual behavior, or another characteristic that might be considered degrading.

The context shows that stigmatized individuals live in search of different ways or strategies for relating. Stigmatized individuals may take their status for granted or play it down, adapting to the community in order to reduce their difference from established cultural norms or back away when faced with a potentially unreceptive environment. Sometimes they may approach groups that share the same stigma, where they will be more accepted and understood, and other times attempt to show that they can be “equal” or “normal”, seeking to overcome their limitations, as for example with persons with disabilities that are able to engage in sports ^{43,44}.

Fear of rejection or prejudice appears to explain this situation, leading the patient to omit the diagnosis or mask the situation. On the issue of manipulation of information by the stigmatized individual, according to Goffman ¹¹, persons that suffer stigma assess their specific characteristic and decide whether to display it, to lie, or to tell the truth, to hide or reveal it to whom, how, and when.

Asymptomatic HTLV-infected individuals may guard total secrecy and not occupy an embarrassing position in most cases. Since HTLV is a sexual, bloodborne, or vertically transmitted infection, these individuals must also choose to whom or how to disclose their status in case of sexual relations, explain why they cannot breastfeed in the case of postpartum women, and explain why they cannot donate blood if so requested.

Symptomatic HTLV carriers, due to aggravation of their condition, may develop total dependence on others for their activities of daily living such as eating, grooming, and personal hygiene (changing adult diapers, bathing, etc.). In such cases, guarding secrecy involves an assessment on what to disclose and to whom and prior elaboration of answers to anticipated questions. That is, they must assess and decide on what may cause less embarrassment. Some find a “way out” by revealing secondary diagnoses, as mentioned. Others deal with more complex situations: How not to reveal a diagnosis to a caregiver? How to keep secrecy on the medications that the caregiver is supposed to administer? Situations of omitting or hiding the diagnosis by individuals infected with HTLV are discussed by Rivemales ³², Orge et al. ³³, Reuter ³⁶, and Zihlmann et al. ³⁷. Santos et al. ⁴² also address the dependence that symptomatic patients can develop in basic activities like walking and eating, causing losses in their quality of life, social isolation, and feelings of worthlessness, shame, and inferiority.

Stigma places blame on the individual and reinforces social division. Daniel & Parker ⁴⁵ refer to the social death of subjects who are (or feel that they are) left out of society. Karamouzian et al. ⁴⁶ also problematize the social death of HIV-positive patients, prior to the physical death, due to the physical and psychological suffering resulting from loss of work, broken family and emotional ties, and feelings of fear, low self-esteem, guilt, and prejudice. Rivemales ³² refer to the social death caused by the emotional loss of friends and family members due to social isolation vis-à-vis the diagnosis.

This scenario can contribute to lack of treatment adherence by the patient. Social production of stigma, prejudice, and inequality generally lead to acts or omissions that jeopardize access by groups to goods and services, characterizing the materialization of injustice and discrimination against a certain group ⁴⁷.

HTLV may be stigmatizing for some persons and not for all. For some, as Goffman ¹¹ explains, the stigma is not due simply to an attribute, but is generated in social relations. According to the author, a stigmatized individual may take the situation for granted, which also explains why there are persons with HTLV who do not feel stigmatized and do not keep their diagnosis a secret.

Brown et al. ²⁷ propose intervention strategies to reduce stigma in HIV-positive individuals, but which can be applied to individuals with any stigmatizing condition. They emphasize the importance of information on the disease through educational material and practices; the strategy to use awareness-raising techniques and the exposure of stigmatized groups to hypothetical situations of individual or collective conflict resolution; counseling the affected persons, strengthening self-esteem and social support for patients to find personal and collective alternatives for coping with their disease condition and its consequences; and finally, contact between groups for direct or indirect

interaction between persons living with stigmatizing diseases and the public in general, contributing to demystifying stereotypes related to the disease. These strategies could also contribute to reducing the stigma in patients living with HTLV.

Stigma and discrimination are considered forms of human rights violations. Article 11 of the *Universal Declaration on Bioethics and Human Rights* of the United Nations Educational, Scientific and Cultural Organization (UNESCO)⁴⁸ states, “*No individual or group should be discriminated against or stigmatized on any grounds, in violation of human dignity, human rights, and fundamental freedoms*”. As stated by Villela & Monteiro¹⁸, stigma compromises the exercise of citizenship, enjoyment of rights, and access to public services. According to Godoi & Garrafa¹⁹, stigma can only be produced or materialized if the other’s dignity is removed, when the other is diminished in that which makes them a human being, if the other is made inferior and considered beneath other human being. According to Bastos⁴⁹, in the social world, stigma updates and reinvents itself, demonstrating the persistence of hierarchies in societies. The fight against stigmatization is thus a key element in strategies for dealing with HTLV.

Final remarks

Stigma is a social construct and results in discrimination, inequalities, and social injustices. Stigmatized individuals suffer unwanted effects and create coping mechanisms, whether through aggressiveness, disguising, escape, denial, or playing down the situation. HTLV-related stigma is a negatively valued social mark related to a downgraded identity. This STI is a public health problem in Brazil, and the low investment in prevention and control of the infection perpetuates its invisibility, reinforcing the stigma and discrimination.

These reflections motivated by our professional experience with patients affected by the disease and based on a literature review was not intended to exhaust the topic, but it did allow shedding light on the discussion on stigma and HTLV. Neither did it attempt to provide a definitive answer to the question in the title, whether HTLV is a stigmatizing STI, but to problematize the infection’s repercussions on persons’ lives. HTLV is an STI that has received relatively little research attention from this perspective, and it is important to suggest possible paths such as educational activities to decrease the invisibility of the infection.

Lack of knowledge on HTLV among many health professionals and the general population, difficulties in access to health services, diagnosis, and follow-up are associated with stigma and difficulties in interpersonal contact, solidarity, and psychosocial and community support. Stigma contributes to increasing the vulnerability of persons with HTLV who suffer from the diagnosis of a sexually transmissible infection that is often unknown and with uncertain evolution, potentially affecting their marital, family, and social life, interfering in breastfeeding, and even evolving to physical incapacity or death.

Confronting the social processes of stigma and discrimination in populations affected by the virus involves social mobilization to expand the visibility of this STI and promote the creation of public policies that can contribute to the prevention of HTLV infection and the promotion of care and treatment and the rights of individuals in situations of vulnerability.

Contributors

The authors participated equally in the article's elaboration.

Additional informations

ORCID: Ionara Ferreira da Silva Garcia (0000-0003-3527-4397); Élide Azevedo Hennington (0000-0001-5280-8827).

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Resumo

O HTLV é um vírus que afeta as células T humanas. O Brasil é o país com o maior número absoluto de casos de HTLV no mundo. Estimativas do Ministério da Saúde apontam entre 700 mil e 2 milhões de pessoas infectadas. A maioria são portadores assintomáticos, porém algumas pessoas podem vir a desenvolver quadros neurológicos degenerativos como a paraparesia espástica tropical, além de leucemia e linfoma. As formas de transmissão e manifestações clínicas como incapacidade motora progressiva, distúrbios geniturinários, além da restrição ao aleitamento materno impactam o cotidiano e podem ser geradores de discriminação social e estigma. O estigma denota violação das normas sociais e reforça o preconceito e as desigualdades. O objetivo deste artigo é discutir o conceito de estigma e sua repercussão em pessoas que convivem com o HTLV. Trata-se de uma reflexão baseada na revisão da literatura sobre o tema e na vivência do atendimento a pessoas afetadas pela infecção e adoecimento. Constatou-se que ser portador do vírus ou adoecer em decorrência da infecção pelo HTLV pode ser estigmatizante para indivíduos que se sentem inferiorizados ao serem acometidos por uma doença potencialmente grave e até mesmo fatal, ainda pouco conhecida e carregada de estereótipos depreciativos. Essa situação pode repercutir negativamente no acesso aos serviços de saúde, na adesão ao tratamento e na busca por direitos. As políticas públicas devem contribuir para mitigar a estigmatização, assegurando o direito de indivíduos em situação de vulnerabilidade pelo HTLV viverem como protagonistas no exercício de sua cidadania.

HTLV; Estigma Social; Preconceito; Cidadania

Resumen

El HTLV es un virus que afecta a las células T humanas. Brasil es el país con el mayor número absoluto de casos de HTLV en el mundo. Las estimaciones del Ministerio de Salud indican que existen entre 700 mil y 2 millones de personas infectadas. La mayoría son portadores asintomáticos, sin embargo, algunas personas pueden llegar a desarrollar cuadros neurológicos degenerativos como la paraparesia espástica tropical, además de leucemia y linfoma. Las formas de transmisión y manifestaciones clínicas como incapacidad motora progresiva, disturbios geniturinarios, además de la restricción en la lactancia materna, tienen un impacto en las personas afectadas y pueden causar discriminación social y estigma. El estigma denota una violación de las normas sociales y refuerza el prejuicio y las desigualdades. El objetivo de este artículo es discutir el concepto de estigma y su repercusión en personas que conviven con el HTLV. Se trata de una reflexión basada en la revisión de la literatura sobre el tema y en la vivencia de la atención a personas afectadas por la infección y enfermedad. Se constató que ser portador del virus o enfermar, a consecuencia de la infección por el HTLV, puede ser estigmatizante para individuos que se sienten subestimados al ser atacados por una enfermedad potencialmente grave e incluso fatal, todavía poco conocida y cargada de estereotipos depreciativos. Esta situación puede repercutir negativamente en el acceso a los servicios de salud, en la adhesión al tratamiento y en la búsqueda de derechos. Las políticas públicas deben contribuir a mitigar la estigmatización, asegurando el derecho de los individuos en situación de vulnerabilidad por el HTLV para que vivan como protagonistas en el ejercicio de su ciudadanía.

HTLV; Estigma Social; Prejuicio; Ciudadanía

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