

# Formative Process of Human Rights for People Living with HIV in Brazil and Its Relation to Social Representation

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## Abstract:

**Background:** Social representations play a fundamental role in resolving internal conflicts within society. They have the intrinsic capacity to transform ideas into collective experiences, promoting interaction and reflection on the condition of these populations. This study is based on the theories of Moscovici and Jodelet, which highlight the importance of social representations in the construction of culture and social integration.

**Materials and Methods:** The research is characterized as exploratory and descriptive, utilizing an integrative literature review and documentary research. Scientific and journalistic articles, as well as legal texts that address the incorporation of human rights into the legal system, were analyzed. Sources were obtained through searches on Google Scholar and SciELO using descriptors such as "HIV," "Human Rights," and "Social Representation".

**Results:** Social representations of PLHIV on broadcast television often perpetuate negative stereotypes, portraying them as highly sexualized and diseased individuals, exemplified by the character Inaiá in the soap opera "Amor à Vida." In contrast, streaming platforms have normalized and humanized PLHIV, disseminating updated information about their life conditions and human rights. The lack of updated scientific dissemination perpetuates stigma and serophobia, hindering adherence to treatment and serological testing. Appreciating representativeness is essential for society to understand the needs of minorities and how these are affected by issues impacting their life conditions. Serial narratives are effective in portraying events and people, strongly influencing how society thinks and acts. The media has the power to convey scientific evidence, addressing social and public health issues, contributing to eliminating prejudices and stigmas.

**Conclusion:** It is crucial that the State and broadcast television adopt public policies for the social representation of PLHIV in their real life conditions. The responsibility to promote the humanization and human rights of PLHIV should not fall exclusively on alternative digital media. The dissemination of scientific information and faithful representation in the media are fundamental to dissipating prejudice and promoting social acceptance of PLHIV.

**Key Word:** Social Representation; HIV; Human Rights; Stigma; Serophobia.

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## I. Introduction

Social representations play a fundamental role in resolving internal societal conflicts. They have the intrinsic capacity to transform ideas into collective experiments through internal and external communications among members of social groups. This process generates interaction and reflection on the condition of these populations and their everyday situations, with the aim of making something previously unfamiliar into something familiar, seeking consensus and feelings of belonging, where people feel free from friction and risks (Moscovici, 2010). It is closely linked to the real understanding of the subject and is supported by the transversal nature of social representations, which have a broad explanatory capacity for complex social

processes. This understanding is based on the narratives of social actors, who express themselves through discourses and artistic and behavioral manifestations, including audiovisual productions, which give form and dimension to social representations (Jodelet, 2018).

In summary, the construction of culture occurs through the process of anchoring, which consists of symbolic references organically incorporated into the human mind, creating meanings and influencing judgment and the social rooting of individuals. This process transforms previous concepts, acting in replicable cognitive integration, culminating in the relationships between different social groups and the formal construction of knowledge on how to express identity and give meaning to representations. The objective is to promote the connection of collectives through dynamics and interactions that allow coexistence in society (TRIANI; BIZERRA; NOVIKOFF, 2017; JODELET, 1990; DOISE, 2002).

When the subject is exposed to the process of representation, they exercise reconstruction in their cognitive system. This involves incorporating the knowledge acquired through social interaction into something that aligns with their personal values. The subject restructures their reality and integrates new conceptions into their mental repertoire, understanding and giving meaning to the reality of others, depending on their social and ideological context. In this way, the subject adapts and seeks to situate themselves in the society in which they live (Parreira et al., 2019).

Both the external and internal layers of the population depend on these processes, as, even with recognition policies, many people still feel unable to interact with society due to the internalization of self-deprecation caused by the widespread dissemination of a distorted image. Simply elevating their status to that of citizens is not enough to dissipate the created caricatures, the paralyzing self-hatred, and the feeling of inferiority. Space is needed for these people to present their real identities, in order to claim recognition, a sense of dignity, and self-pride (Taylor, 2000).

Social representations have an importance that transcends what is imagined, and this is proven by the four functions subordinated to this phenomenon: the Knowledge Function, the Identity Function, the Orientation Function, and the Justification Function. The first function seeks to assimilate practical knowledge that is consistent with values and cognitions, allowing social actors to understand and explain reality. The second aims to position the population regarding the social identity of a particular group, bringing them closer to society to protect their specificity. The third function, orientation, aims to generate in-depth knowledge about people in the social field, defining what is appropriate in terms of treatment and what is unacceptable. And finally, the justification function aims to preserve the group in society, justifying behaviors, dissolving social paradigms and common sense. These four subordinated functions prevent individuals from being stereotyped and ensure the fundamental right to be different from others, regardless of the subject's condition, contributing to dissipating discrimination and social distancing, and reaffirming their positions as citizens (ABRIC, 2000).

It is important to mention that social representation needs to be authentic for people living with HIV, as it serves as a basis for the fight for the right to integrate an autonomous social group, formed and defined by PLHIV, even if they are also part of other subgroups and social organizations. In practice, this means that although numerous, those living with HIV do not constitute a cohesive group and remain invisible, without a clear social identity, often excluded by members of the main group to which they are subordinated, placing them at a lower hierarchical social and cultural level, exposed to discrimination and prejudice, including by other minorities.

## **II. Material And Methods**

The present study aims to research the social representation of HIV-positive individuals, a term used to designate a person who has tested positive for HIV. The dialogic of representation seeks to critically present the social condition to which these groups are subjected, promoting the transmission of knowledge about this social issue (ARAÚJO, 2018).

Thus, the problem addressed in this work relates to social representation as a means of breaking social paradigms, impacting those who do not live with the virus through an educational process. This process stems from the subordinate functions of exposure to updated knowledge about lifestyle and technological advancements in treatment and non-transmissibility, as well as generating a sense of belonging to society among people living with HIV (PVHIV). It diffuses human rights (HR) and humanizes HIV-positive individuals by representing their living conditions in the contemporary scenario.

Regarding the objectives, this is an exploratory research, aiming to develop, modify, and clarify concepts and ideas about a particular issue, as it intends to provide an overall, approximate view of a specific fact with limited publications (AAKER et al., 2004; GIL, 2022). It is also characterized as descriptive research because it aims to describe a particular phenomenon (GIL, 2022): the effects of faithful representation of PVHIV life and the impacts on promoting HR and humanizing this population. According to GIL (2022), "there are researches that, although defined as descriptive based on their objectives, end up serving more to provide a

new perspective on the problem, which brings them closer to exploratory research.” Therefore, the present research can be classified as exploratory and descriptive, as they are complementary and work in synergy.

Regarding the procedures, a bibliographic research was conducted to construct the theoretical framework through an integrative literature review, allowing for a broad analysis of empirical data from a contemporary perspective (SOUZA; SILVA; CARVALHO, 2010). The literature review comprises scientific and journalistic articles, as well as classical literature on the topic of representation. The works selected for the research were retrieved through searches in Google Scholar and SciELO databases with the descriptors “HIV,” “Human Rights,” and “Social Representation.” Documentary research was also applied to legal texts addressing the incorporation of HR into the legal system and aiming to protect minorities against discrimination.

### **III. Result**

#### **Social Representation of PLHIV**

The objective of social representation is to portray the reality of marginalized minorities, considering scientific, technological, and social advances. However, in the case of people living with HIV, open television often portrays them in a stereotypical manner, as highly sexualized and sick individuals, in a state of mere survival, as seen in the soap opera *Amor à Vida*, aired by Rede Globo de Televisão from May 2013 to January 2014. In this soap opera, the character Inaiá was portrayed as a vulgar and promiscuous woman upon being diagnosed with HIV, leading to her exclusion from society. In contrast, streaming platforms currently normalize and humanize characters living with HIV, disseminating knowledge about their real living conditions and providing access to human rights and fundamental guarantees as members of society.

Individuals who are HIV-positive suffer from various types of prejudice stemming from a lack of understanding in common sense. There is a social convention that HIV-positive people represent a significant biological risk, resulting in a stigma known as serophobia, which is the discrimination against a person simply for having a positive HIV status. The lack of updated scientific dissemination to the public prevents the change of this conception. These prejudices lead to behaviors ranging from distancing to job loss, actions solely imposed by the individual's infectious condition. Furthermore, many HIV-positive individuals may not fully understand the consequences of the condition for themselves and their social group, which can decrease adherence to treatment. Misinformation is a factor responsible for the lack of HIV serological testing among the general population due to the fear of a positive result and the misconception of a death sentence or survival (Jesus, 2017; UNAIDS, 2018).

In recent years, studies on HIV have broken paradigms regarding viral behavior, cellular tropisms, aggravating factors, and the action of drugs in the infected individual. When a patient is in treatment, no viral genetic material is detected, with no active copies in the body, and the term “undetectable” is used. The concept of “undetectable equals untransmittable” (U=U) emerged, completely changing the understanding of HIV transmissibility (UNAIDS, 2018). Unfortunately, this information is not widely disseminated, and the power of the media and artistic works is not used to spread this information, leaving it restricted to academia (Ianni, 2004). It is worth noting that the media has the ability to transmit scientific evidence by addressing social and public health issues, which can change the recipient's life by eliminating prejudices and stigmas perpetuated by an outdated society (Latour, 2012).

The appreciation of representativeness is essential for society to understand the needs of minorities and how these groups are affected by issues that directly impact their living conditions. Serialized narratives are an effective means of portraying events, people, and objects, and have the power to influence society prescriptively, exerting a strong influence on how people think and act. By sharing mental processes, they affect how people make decisions and organize their lives, contributing to the construction of broader knowledge about the social representation of people living with HIV, challenging common stereotypes and prejudices against these individuals and serving as a powerful cultural agent (Moscovici, 2010).

#### **Relationship Between Human Rights and PLHIV**

The perception of difference, in the legal sphere, requires a universal set of values, and since there is no universally valid instrument to measure the social value of practices and characteristics of groups or individuals, it becomes necessary to establish cultural interpretations that validate their social importance. It is essential to have representativeness and demonstrate the living conditions of people living with HIV today, rejecting the stereotypical representation of sick and doomed individuals. However, for the interpretations and ways of life of the group to be valued, the group must exert a symbolic and cultural force that allows it to influence the public sphere, demonstrating the neglect of the reputation of its members and promoting the acceptance of their demands through social movements (Honneth, 2007).

People living with HIV (PLHIV), in particular, are not treated as subjects of human rights and are excluded from the justice system. This violates their humanity and reduces them to the role of objects of discourse, exposing the fragility of this approach in ensuring rights and promoting equality among the oppressed

in society. For this reason, they seek recognition of their citizenship by the legal system, to achieve equality with other citizens and be socially valued, no longer being excluded due to their specific conditions. However, the humanization of this group is limited by the interpretation of international human rights norms, as policies and rights protecting against the decriminalization of PLHIV are neglected, and the international legislation dedicated to protecting this group is flawed (Santos, 2014; Honneth, 2007; Nagamine, 2019).

It is necessary to understand and disseminate the rights of PLHIV, as the violation of these rights has a negative impact on individuals, leading them to avoid seeking specialized treatment and continuing with treatment, which increases viral load and transmissibility, resulting in AIDS-related illnesses and deaths. This violation of rights is also disastrous concerning the Sustainable Development Goals (SDGs), which aim to eradicate AIDS as an infectious disease (UN, 2021). Therefore, it is imprudent to neglect the right to protection against discrimination, sexual education, and prevention through representativeness (Ferraz; Paiva, 2015).

### **Media Social Representations of PLHIV and the Process of Forming Human Rights**

A significant portion of media material is influenced by a conservative editorial stance, with few media outlets addressing the expansion of human rights from a critical and objective perspective, promoting civil and social rights. Digital Information and Communication Technologies (DICT) allow the receiver to seek content guided by a counter-hegemonic perspective on human rights, enabling the horizontalization and diversity of production. The population begins to exercise citizenship when they understand that communication is a fundamental part of all human relations, but its realization can only occur with mutual respect mediated by dialogue and the exposure of their political positions (Mendonça, 2015).

The recognition of human rights results from social battles fought to ensure that the status of being human is not temporary but permanent, representing the plurality of thoughts and recognizing the importance of these rights in the formation of the citizen (Mendonça, 2015). Alternative digital media can be used as a tool to disseminate human rights, constructed from a critical and integrative perspective focusing on emancipatory social practices. This media understands that sustainable development and human rights are complementary and oppose the homogenization, invisibility, centralization, and hierarchization of traditional institutional practices (Flores, 2008).

It is crucial to understand and disseminate the rights of people living with HIV (PLHIV) to minimize the violation of these rights, which have a significant negative impact on their lives. When these rights are violated, PLHIV may avoid seeking specialized treatment, resulting in an increase in viral load and transmissibility of the virus. This can lead to more cases of AIDS and deaths, hindering the eradication of this infectious disease, contrary to the UN's Sustainable Development Goals (SDGs) (UN, 2021). It is imprudent to neglect the right to protection against discrimination, as well as to compromise sexual education and prevention through representativeness (Ferraz; Paiva, 2015).

### **Human Rights Pathway for PLHIV in the Brazilian Context**

There are shortcomings in the application and validity of human rights, as is the case with international treaties and conventions, which should guide domestic legislation but present insufficient content and encourage a legislative logic intertwined with discrimination and exclusion of the rights of people with HIV due to the lack of explicit provisions. Although the Universal Declaration of Human Rights (UDHR) has established the universal protection of human rights since 1948, based on principles of freedom, equality, and non-discrimination, it is necessary to point out that its application is still limited, as it does not explicitly mention PLHIV in its articles on the scope of rights and the prohibition of discrimination, allowing its application to this population by analogy, similar to other issues addressed in this legislative instrument (Lelis; Galil, 2018).

In 1988, Brazil adopted World AIDS Day, celebrated on December 1st, in response to the outcry of PLHIV who, during the peak of the pandemic, were abandoned and dying in large numbers (Araujo, 2016). With the social relevance of the epidemic and thanks to the struggle and representativeness of these individuals, health professionals, and civil society members produced the Declaration of Fundamental Rights of People with AIDS in 1989, based on the UDHR, emphasizing human dignity, confidentiality, and access to public health (Brazil, 2021). Although it did not have the force of law, the document guided the consensus on the proper treatment of HIV carriers as citizens, as their numbers grew exponentially. However, for years, PLHIV were not specifically addressed in the legal framework in legislation dealing with social rights and human rights.

Although Brazil has committed to non-discrimination of its citizens as a signatory of some international pacts, even today, people with HIV continue to be socially segregated due to the lack of explicit determination. For example, the International Covenant on Economic, Social, and Cultural Rights (ICESCR), incorporated into the national legal system by Decree No. 591 of July 6, 1992, aims to eliminate discriminatory acts but does not explicitly mention PLHIV in its Article 2 (Brazil, 1992a). The International Covenant on Civil and Political Rights (ICCPR), incorporated by Decree No. 592 of July 6, 1992, complements the protection of individuals living with HIV, aiming to prohibit distinction and unequal treatment, but without directly referring

to them (Brazil, 1992b). Additionally, the American Convention on Human Rights, incorporated into Brazil by Decree No. 678 of November 6, 1992, was the official gateway for human rights precepts into Brazilian legislation, bringing a new social dynamic to the country and humanizing various minorities to eliminate discrimination (Brazil, 1992c). Given the historical context of these pacts and the HIV pandemic, a virus still unknown to science at the time, they were unable to provide equality between PLHIV and HIV-negative individuals, despite technological advances regarding treatments and life expectancy of this group.

The landscape changed drastically with the publication of the Swiss Protocol, which stated that people living with HIV, when on treatment and with an undetectable viral load, would not be able to transmit the virus (Vernazza et al., 2008). The Swiss National AIDS Commission published in January 2008, in the Swiss Medical Bulletin, that "treatment as prevention" would be the best strategy to contain infections, which prompted the PARTNER study, which analyzed and confirmed the hypothesis raised by the Swiss protocol (Cohen et al., 2011), changing the way people living with HIV were perceived by science, and adopting the concept of functional cure.

With increased visibility through studies and media content, the Inter-American Convention Against All Forms of Discrimination and Intolerance emerged, a Brazilian initiative that became an international document with the power to cause a significant social impact and in the national legal system. The convention was approved by the General Assembly of the Organization of American States (OAS) in 2013 and has a binding character as an international treaty. It was the first to expressly address protection against multiple or extreme forms of discrimination and intolerance for people in a stigmatized infectious condition (Lelis; Galil, 2018; OAS, 2013).

#### **IV. Discussion**

##### **Materialization of Representativeness and Positive Advances**

On March 1, 2014, UNAIDS initiated the celebration of Zero Discrimination Day, an important milestone for the visibility of people living with HIV (PLHIV), who frequently suffer from social and structural discrimination and are often criminalized (UNODC, 2014). Through the #zerodiscrimination campaign on social media, this initiative promotes equality for these individuals and raises media awareness of their cause.

During this period, new studies and results on HIV treatment were at their peak, aiming to understand whether a person undergoing treatment could transmit the virus. Additionally, as a result of the OAS Convention, Brazil enacted Law No. 12,984 on June 2, 2014, which defines discrimination against people infected with HIV and AIDS carriers as a crime, including practices such as disclosing serological status and denying employment due to the serological condition of PLHIV. This was the first concrete action to protect these individuals as citizens in society (Brazil, 2014).

The following year, in 2015, the 17 Sustainable Development Goals (SDGs) emerged as a universal initiative by the UN to address the world's most urgent environmental, political, and economic challenges, with the intention of fulfilling a set of goals by 2030 (Agenda 2030) to end poverty, protect the planet, and ensure peace and prosperity for all people. Among these goals, health and well-being, quality education, reducing inequalities, and justice stand out, as they directly relate to the issues discussed in this study about the challenges faced by people living with HIV, who are often excluded from social, emotional, and professional life due to misinformation and prejudice (UN, 2021).

Recently, a significant legislative innovation was approved, Law No. 14,289 of January 3, 2022, which mandates the preservation of confidentiality regarding the HIV status of PLHIV in telematic and media communications, providing important protection for people living with HIV infection. This legal provision has significant social impact and is a powerful instrument for defending the rights of PLHIV (Brazil, 2022c). The use of media as a means to increase the visibility of PLHIV is another important way to promote the representativeness of this group and affirm their protection as citizens. Social networks, including TikTok, Instagram, Facebook, WhatsApp, and YouTube, are used as independent channels to showcase the reality of this population's lives. It is important to highlight that the representativeness of PLHIV is understood in real worlds, abstracted from symbolic dimensions (Gontijo; Erick, 2017), and that people living with HIV are bearers of human rights that require proper representativeness and protection.

#### **V. Conclusion**

Social representation, as demonstrated throughout this study, has subordinate functions that lead individuals to a formative process with the potential to transform common sense and eliminate stigmas about the living conditions of people living with HIV. Open television broadcasters do not concern themselves with actively addressing these issues, nor are there public policies from the State that support the dissemination of advertisements and institutionalize the representation of scientific advances related to the theme. Thus, the responsibility falls on alternative digital media to recognize people living with HIV (PLHIV) as integral members of society and to propagate human rights through representation in media content aimed at embracing

this cause. The information presented has the capacity to dispel prejudices, effectively promoting self-acceptance within this group, eliminating guilt and self-hatred by understanding that their context does not make them biological weapons. This normalizes and humanizes the individual and influences others to understand that people with HIV lead normal lives, expunging the prejudice that had been ingrained in their perceptions.

Given all the above, it is evident that the State must not shirk its responsibility as the bearer of the obligation to provide a “Welfare State” to all citizens, as prescribed by the Federal Constitution and the International Pacts and Conventions, to which Brazil is a signatory, which deal with Human Rights. It is necessary to create public policies for the social representation of PLHIV in their true living conditions. Open television broadcasters should also adopt similar measures when representing this population in their media content to avoid generating stereotypes and to support the humanization and promotion of Human Rights.

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