
Media evolution in HIV narratives through the ages

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ABSTRACT

Since the 1980s, the evolution of media narratives about HIV/AIDS reflects significant changes in public perception and disease management. Initially linked to stigma and prejudice, AIDS was treated as a death sentence and moral punishment, especially towards marginalized groups. Over time, narratives transformed, particularly after the introduction of antiretroviral therapy (HAART) and the I=I (Undetectable = Untransmittable) concept, highlighting AIDS as a manageable chronic condition. This study reviews the literature on changes in media representations of HIV/AIDS, comparing early epidemic narratives with post-HAART and post-I=I narratives. Results indicate a shift from stigmatizing narratives to more educational and inclusive representations, reflecting scientific advancements and reduced social stigma.

Keywords: HIV; Narratives; Media; Stigma; Evolution.

INTRODUCTION

Since HIV became an epidemic in the 1980s, the way the issue is addressed through the media, whether broadcast, mainstream, or streaming has transformed, moving from an obscure limbo where the essence of the problem was not discussed, to the present day, when presentations of the HIV/AIDS issue have an educational focus in the media, reaching a significant portion of the world's population. This is especially true when considering streaming platforms as tools for public health dissemination and communication.

The early 1980s were marked by a notable increase in cases of various opportunistic diseases and rare infections, especially among men who had sex with men. This drew the attention of the medical community. On June 5, 1981, the United States Centers for Disease Control and Prevention (CDC) reported the first cases of an unusual disease (later identified as AIDS) affecting gay men in Los Angeles.

Initially predominantly associated with homosexual men, AIDS soon proved to affect various groups, including intravenous drug users, hemophiliacs, and eventually heterosexuals. HIV tests were developed in the mid-1980s, allowing more effective tracking of the infection. Awareness campaigns about safe practices and the importance of condom use were intensified.

The AIDS epidemic was accompanied by significant stigmatization of the LGBTQ+ community and people infected with HIV/AIDS, resulting in discrimination and prejudice. This group, together with health activists, played a crucial role in raising awareness about AIDS and promoting research and treatments. However, the governmental response was initially slow in many places.

The impacts of the virus's spread profoundly affected global society, not only in health but also in terms of human rights, social issues, and activism. The historical context of the epidemic is complex and multifaceted, with significant challenges faced during its emergence and evolution, as was the case with the media of the time.

The main objective of this article is to analyze and compare the changes in media narratives about HIV/AIDS from the beginning of the epidemic to the present day. The research aims to understand how representations of the disease have evolved, reflecting significant transformations in public perception, disease management, and the reduction of social stigma.

Initially, AIDS was treated as a death sentence and a moral punishment, especially for marginalized groups. With the advent of antiretroviral therapy (HAART) and the consolidation of the U=U concept (Undetectable = Untransmittable), narratives began to portray AIDS as a manageable chronic condition. This study seeks to demonstrate how these changes in media narratives have contributed to a more educational and inclusive view of the disease, reflecting scientific advances and the reduction of stigma over time.

MATERIALS AND METHODS

For the analysis of narratives about HIV/AIDS, a literature review was conducted in the databases U.S. National Library of Medicine National Institute of Health (PubMed/Medline), SciELO, and Google Scholar due to their popularity among students. For better integration of the results, the intersections of the following descriptors were used: HIV, Narratives, AIDS, Media Products.

The search covered publications without any restriction on period and language, with these being in English and Portuguese. Upon completion of the initial search phase, the results were analyzed based on title and abstract to verify their relevance to the proposed theme, with the inclusion criterion being all articles that addressed the narratives of HIV/AIDS.

Subsequently, the selected articles were read in full and included in the study. The exclusion criterion used was non-adherence to the theme, lack of a defined methodology, and literature review articles.

HIV/AIDS NARRATIVES AT THE BEGINNING OF THE PANDEMIC

With a critical and analytical analysis of the narratives about HIV/AIDS at the beginning of the epidemic, it can be highlighted how the constant use of metaphors and stereotypes associated with AIDS influenced the public perception of the disease and the people affected by it, as all were linked in the sense of presenting the condition as incurable, contagious, and fatal (Daniel, 1994).

In the initial context of the epidemic, many narratives surrounding AIDS were permeated by negative metaphors, often laden with stigma and fear. The disease was initially linked to social stigmas, often portrayed as a punishment for morally

condemnable behaviors. This negative association contributed to the marginalization of people living with HIV/AIDS (Sontag, 2007).

Additionally, the language used at the time to describe AIDS often reinforced harmful stereotypes, contributing to discrimination and social isolation. It was crucial to dissociate the disease from moral and stigmatizing judgments, emphasizing the need for a more objective and compassionate approach in communication about HIV/AIDS during that period.

The metaphors surrounding AIDS impacted public policies and societal attitudes towards virus carriers. By challenging these metaphorical representations, Sontag (2007) seeks to promote a fairer and more empathetic understanding of the disease, encouraging a shift in narratives beyond the initial stigma.

These analyses provide a solid foundation for critical reflections on how narratives can shape the perception of diseases and influence social responses. At the beginning of the HIV/AIDS epidemic, the social stigma issues were quite significant and challenging for the people affected by the disease. AIDS emerged in the 1980s and 1990s, and during this period, a series of social stigmas enveloped the condition, profoundly impacting the lives of seropositive individuals (Bessa, 1997; Sontag, 2007).

In this context, it could be said that a person living with HIV/AIDS at the time was pejoratively called "aidética" in Portuguese and considered to be in a state of civil death. From the perspective of PLHIVs, the term can be used symbolically to describe the discrimination, stigma, and social exclusion that some face due to their serological condition. This does not refer to a formally legal sanction, but rather to an expression that highlights social, legal, and emotional obstacles often imposed as a result of positive HIV serology (Daniel, 1994).

PLHIV have been exposed to dehumanizing situations since the beginning of the epidemic and have been affected in various aspects of their lives, including interpersonal relationships, employment opportunities, access to health services, and participation in society. This social exclusion can be metaphorically compared to a living death, as it implies the loss or restriction of certain aspects of daily life (Daniel; Parker, 1991).

It is important to highlight that this metaphor reflects the ongoing struggle against the stigma associated with HIV/AIDS and underscores the importance of promoting understanding, empathy, and respect for people living with this condition. Awareness of the impact of stigma would be fundamental to creating a more inclusive society and supporting the needs of people affected by HIV/AIDS when it all began. However, society

chose to follow a path that would lead to the ethical and moral destruction of individuals (Sontag, 2007).

In this context, when addressing the dissemination of discourses, which refers to the emergence of a considerable amount of expressions in different social sectors, as well as the dissection of these manifestations, the concept of discursive epidemic is found. This can be understood as a set of imaginary constructions generated and shared discursively by different social segments, in a context of mediatization and excess of statements on a specific theme, reflecting certain predominant perspectives in a specific society and moment.

This conception can be employed by considering the volume and flow of statements in social spheres and the power to propagate over time through the exercise of interdiscursivity, through which these expressions solidify in discursive memory. By the proliferation and long-term repetition, with difficulty of mutability, these constructions are consolidated in collective memory so markedly that they are often evoked. These imaginary constructions were directly related to HIV/AIDS (Bessa, 1997).

The main elements that linked the discursive epidemic to the commonsense imagination were those that tended to decimate the identity of PLHIV, disconnecting it from the reality of the population that did not live with the virus or was not ill due to opportunistic diseases that arose from the facilitation of AIDS. These elements are directly related to the notion of value, morality, fear, and ignorance, being:

a) Association with Marginalized Behaviors: Initially, AIDS was often associated with groups considered marginalized by society, such as gay men, intravenous drug users, and sex workers. This association contributed to the stigmatization of these groups and individuals affected by the disease;

b) Moral and Religious Stigma: There has been a tendency to associate AIDS with moral and religious judgments. Some depictions suggested that the disease was a divine punishment for behaviors deemed immoral. This moral stigma exacerbated the suffering of people living with HIV/AIDS, placing an additional burden of guilt and shame upon them;

c) **Fear of Transmission:** Lack of knowledge about HIV transmission contributed to widespread fear and discrimination. Many people were hesitant to interact with individuals who were HIV-positive due to misconceptions about how the disease spread, which intensified social stigma;

d) **Discrimination in Various Contexts:** People living with HIV/AIDS, known as seropositive individuals at the time, faced discrimination in various spheres of life, including the workplace, healthcare services, and even within family contexts. This discrimination was partly fueled by a lack of understanding about the actual transmission of the virus;

e) **Stigmatizing Language:** The language used to refer to AIDS often carried stigma. Pejorative and discriminatory terms contributed to the creation of negative narratives surrounding the disease, influencing how society perceived and treated people with HIV/AIDS.

Therefore, it can be observed that the narratives shared several common characteristics, as shown in Chart 1.

Chart 1 – Common characteristics of pre-HAART narratives

Characteristics	Description
Discursive epidemic	The epidemic becomes speculative, lacking impartiality across various communication channels (TV, cinema etc.).
Stereotyped narratives	In addressing the theme, PLHIV (People Living with HIV) were commonly associated with fear, guilt, and reinforcement of the death sentence upon HIV infection, or social exclusion, specifically linked to sick individuals. There was no room for prevention, as it generated fear of virus discovery.
Accounts/narratives of illness and death from the syndrome	The works, especially audiovisual ones, attribute a death sentence to PLHIV, presenting characteristic aspects of terminal illness in the characters and a fear regarding testing and knowledge of their serology.

Source: Developed by the author based on research (Silva, 2024).

POST-HAART NARRATIVES

Post-HAART narratives refer to media productions that emerged after the introduction of combination antiretroviral therapy (HAART) in the treatment of HIV/AIDS, commonly known as the "cocktail." Combination antiretroviral therapy involves administering different antiretroviral medications simultaneously to inhibit the replication of the human immunodeficiency virus (HIV) in the body (Chun et al., 1997).

Before the advent of HAART, HIV infection was often associated with rapid progression to acquired immunodeficiency syndrome (AIDS) and significantly reduced life expectancy. However, with the development and widespread implementation of HAART starting in the 1990s, the management of HIV infection underwent a significant transformation (Fischl et al., 1990).

Post-HAART narratives highlight stories of people living with HIV/AIDS who have experienced the successful introduction of HAART into their lives. These narratives often address aspects such as improved quality of life, viral load suppression, increased CD4 cell count (immune system cells), prevention of AIDS-related complications, and in many cases, the transformation of HIV into a manageable chronic condition (Sousa, 2016).

It is important to note that while HAART has been a significant breakthrough in the treatment of HIV/AIDS, post-cocktail narratives may also address ongoing challenges such as medication side effects, social stigma, psychosocial issues, and the impact of the condition on daily life.

These narratives have been extremely important for a more comprehensive understanding of the experiences of people living with HIV/AIDS in a post-cocktail context, highlighting both the progress made and the persistent challenges associated with the ongoing management of HIV infection. They also play a crucial role in breaking down stigmas associated with HIV/AIDS in society (Fonseca, 2019). This narrative phenomenon is embedded in literary, audiovisual, and content production from the period spanning 1990 to 2016, with the latter year marked by the affirmation and establishment of the Undetectable = Untransmittable (U=U) concept.

Here are some ways these narratives contribute to combating stigma:

a) **Normalization of HIV as a Manageable Condition:** Post-HAART narratives highlight the transformation of HIV from a death sentence to a manageable chronic condition. This helps demystify the notion that living with HIV is automatically associated with a debilitating life;

b) **Reduction of Fear of Transmission:** With the success of antiretroviral treatments in viral suppression, post-HAART narratives emphasize effective prevention of HIV transmission. This helps reduce the irrational fear associated with contact with people living with the virus;

c) **Active Participation in Society:** By narrating stories of individuals who live fulfilling lives, work, have healthy relationships, and families, post-HAART narratives challenge negative stereotypes. This helps break the idea that people with HIV should be excluded or isolated;

d) **Combatting Social Stigma:** By sharing personal experiences, post-HAART narratives humanize the condition and foster empathy. This humanization is crucial for combating social stigmas, as people are more likely to empathize with personal stories than abstract statistics;

e) **Education and Awareness:** Post-HAART narratives are a powerful educational tool. By sharing accurate information about HIV, its treatment, and the reality of people living with the virus, these narratives help debunk myths and ignorance that often fuel stigma;

f) **Encouragement for Testing and Early Diagnosis:** By highlighting that treatment is effective and that living with HIV does not prevent a fulfilling life, post-HAART narratives

encourage testing and early diagnosis. This is essential to halt the spread of the virus and reduce stigma associated with serostatus.

In summary, post-HAART narratives have had and continue to have a significant impact on changing attitudes and promoting acceptance and inclusion of people living with HIV in society. Many productions after 2016 still follow this narrative formula, which is more informed, compassionate, and stigma-free regarding HIV/AIDS. Table 2 describes the main characteristics that define post-HAART narratives, distinguishing this narrative period from how things were addressed in the pre-HAART era.

Chart 2 – Common characteristics of post-HAART narratives

Characteristics	Description
Decentralization of the theme	The HIV/AIDS epidemic of the 1980s and 1990s ceases to be thematized, either fully or partially.
Memory narratives	When thematized, the HIV/AIDS epidemic is referenced through experiences from that period. There is a reminiscence that points to the feeling of "back then, we used to live like this."
Narratives of the "chronification" of the syndrome	With the status of a "chronic illness" following the advent of antiretroviral therapy, intrinsic issues related to living with HIV/AIDS are portrayed in the works: the presence of medications, serodiscordant relationships, personal experiences with the virus, disclosure or concealment of serostatus, etc.

Source: Fonseca, 2019.

POSITIVE NARRATIVES

The revolutionary concept I=I, which establishes that an undetectable viral load prevents sexual transmission of HIV, has brought substantial transformation to conventional approaches to the virus. The "Undetectable = Untransmittable" (U=U) concept emerges as a campaign and movement highlighting scientific evidence that a person living with HIV who achieves and maintains an undetectable viral load through antiretroviral treatment (HAART) cannot sexually transmit the virus to their partners. This understanding is based on a series of studies, including the HPTN 052 Study, which demonstrated a correlation between effective viral suppression and reduced HIV transmission risk (Vernazza et al., 2008; Cohen et al., 2011).

The central idea behind U=U is to challenge stigma surrounding HIV, offering a positive and empowered message to people living with the virus. The campaign emphasizes the importance of HAART as an effective means to control the virus, improve health, and crucially, prevent transmission (Mendonça, 2015).

Moreover, U=U has had a significant impact on how society perceives and relates to HIV. It has contributed to a paradigm shift, highlighting that successful treatment not only benefits the individual with HIV but also has positive implications for HIV prevention at a population level.

This approach has been instrumental in promoting healthy relationships, reducing stigma associated with HIV, and educating about the effectiveness of antiretroviral treatment. U=U is widely endorsed by health organizations and has been a valuable tool in the fight against HIV-related stigma and discrimination (Ferraz; Paiva, 2015).

Post-U=U narratives have emerged as a powerful tool in modifying attitudes and social beliefs related to HIV, possessing distinct characteristics that reflect significant changes in understanding and the lives of people living with the virus (UNAIDS, 2018). Here are some common characteristics of these narratives:

- a) **Deconstructing Stigma:** Post-U=U narratives aim to dismantle the stigma surrounding HIV, emphasizing the message that an undetectable viral load means a person with HIV cannot transmit the virus. This helps change perceptions and negative attitudes associated with HIV;
- b) **Emphasis on Health and Well-being:** The stories highlight not only the non-transmissibility of HIV but also emphasize the overall health and well-being of people living with the virus. This includes addressing access to treatment, emotional support, and the fulfilling lives that many people with HIV lead;
- c) **Inclusion of Diverse Characters:** Inclusive narratives feature characters with HIV from various ethnic groups, sexual orientations, and gender identities. This reflects the diversity within the HIV-affected community;

d) **Realistic and Science-Informed Approach:** Post-U=U narratives aim to be informed by solid scientific evidence, conveying accurate information about HIV treatment and virus transmission. This helps combat misinformation and myths surrounding HIV;

e) **Exploration of Relationships:** Stories explore interpersonal relationships, including friendships, romantic partnerships, and family dynamics, highlighting how knowledge of U=U impacts dynamics and overcomes challenges related to stigma;

f) **Involvement of Experts and Activists:** Some narratives incorporate the perspectives of HIV experts, activists, and healthcare professionals to ensure accurate and educational representation of the topic. This strengthens the message of U=U;

g) **Influence on Public Discourse:** Post-U=U HIV narratives have an impact on public discussions about sexual health, highlighting the importance of awareness, testing, and treatment for an effective approach to HIV prevention and management.

These characteristics reflect a movement towards more accurate and positive representation of people living with HIV, contributing to the reduction of stigma associated with the condition and promoting a more compassionate and informed understanding. The concept U=U (Undetectable = Untransmittable) has been increasingly addressed in the media, playing a crucial role in reducing stigma around HIV and promoting accurate information about virus transmission. Here is some information on how U=U is addressed in the media (UNAIDS, 2018):

a) **Public Health Campaigns:** Many countries have developed public health campaigns that emphasize the message that people with an undetectable viral load do not transmit HIV.

These campaigns include advertisements on traditional media such as television, radio, and print, as well as on digital platforms;

b) **Interviews with Experts:** The media often conducts interviews with HIV specialists, doctors, and activists who explain and promote the U=U message. These interviews are conducted on television programs, radio, and podcasts;

c) **Inclusion in Entertainment Narratives:** TV shows and movies have begun to incorporate characters living with HIV and addressing U=U as part of their stories. This contributes to the normalization of the concept;

d) **Digital Media and Social Networks:** Digital platforms, including social media, are used to share information about U=U. Educational videos, informative posts, and infographics are widely disseminated online;

e) **Personal Testimonials:** People living with HIV share their stories and personal experiences on blogs, online videos, and articles, highlighting how U=U has positively impacted their lives;

f) **Debunking Myths:** The media plays a role in debunking myths surrounding HIV. Reports and articles often address common misconceptions and highlight the science behind U=U.

g) **Collaborations with Health Organizations:** Many media outlets collaborate with health organizations and HIV experts to ensure the accuracy of the information presented. These partnerships help provide consistent and reliable messages.

Systematizing the knowledge above, we have the following characteristics of positive narratives (post-U=U):

Chart 3 – Characteristics of positive narratives (post-U=U)

Characteristics	Description
Humanization of people living with HIV and guidance for the general population	From the year 2016 onwards, the HIV/AIDS pandemic began to be seen as a manageable condition.
Didactic narratives	The narratives tend to present scientific facts and guidance, removing all power from common sense regarding the subject matter.
Accounts/narratives of normalization and breaking stereotypes	The works portray characters and situations to teach current issues about HIV, such as the U=U concept, quality of life and longevity, serodifferent relationships without barriers or difficulties regarding serology, prevention methods, and treatment.

Source: Developed by the author based on research (Silva, 2024).

The positive impact of U=U in the media is evident in changing perceptions about HIV, contributing to a more accurate and empathetic understanding of people living with the virus. The use of the U=U (Undetectable = Untransmittable) concept in streaming series can vary depending on the series' themes, narrative approach, and creators' commitment to accurately representing HIV-related issues. Some series, especially those exploring health, sexuality, and relationship themes, have addressed HIV-related issues, including the concept of U=U. However, the presence of this specific concept may not be universal across all productions (Callon, 1984; Latour, 2012; Mol, 1999).

CONCLUSION

The trajectory of media narratives on HIV/AIDS reflects the evolution of understanding and treatment of the disease over the past decades. Since its emergence in the 1980s, marked by stigma, fear, and misinformation, to contemporary narratives emphasizing the chronicity of HIV and the breaking of stigmas, a significant transformation in how society views and treats this condition is observed.

Initially, the HIV/AIDS epidemic was accompanied by negative metaphors and harmful stereotypes that contributed to the marginalization of affected individuals. Narratives were permeated by a sense of inevitability of death and social exclusion,

reflecting the panic and lack of knowledge of the time. However, the introduction of combination antiretroviral therapy (HAART) and scientific advancements transformed HIV management, drastically altering narratives surrounding the disease.

Post-HAART narratives highlighted the possibility of living a full and healthy life with HIV, emphasizing the chronic nature of the syndrome and the importance of treatment. The revolution brought by the concept U=U (Undetectable = Untransmittable) played a crucial role in breaking stigmas by demonstrating that an undetectable viral load prevents sexual transmission of the virus. This paradigm shift in media narratives was essential in promoting a more positive and informed view of HIV/AIDS.

Contemporary productions not only destigmatize HIV but also educate the public on the importance of treatment, effective prevention, and the rights of people living with the virus. Inclusive narratives informed by scientific evidence contribute to normalizing HIV as a manageable condition, encouraging testing, early diagnosis, and promoting empathy and understanding.

In summary, the evolution of media narratives on HIV/AIDS demonstrates significant progress in combating stigma and discrimination. The more objective, compassionate, and informed approach reflects a transforming society, one that is more aware and supportive. Analyzing changes in narratives over the years highlights the positive impact of science, activism, and media in building a fairer and more empathetic understanding of living with HIV/AIDS. This narrative transformation not only enhances the quality of life for people living with HIV but also strengthens global public health by promoting education, prevention, and social inclusion.

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