

HIV COUNSELOR PERSPECTIVES

HIV Stigma Today

Introduction

HIV/AIDS is one of the most stigmatized illnesses in recent history. The intensity and prevalence of negative beliefs, attitudes, and actions toward HIV-positive people have made HIV unique, shaping responses to the epidemic from the individual to public policy level. Although the expressions of HIV-related stigma have changed over time, it remains as one of the most stubborn and pervasive obstacles to curbing new infections. In 2010, almost 30 years into the epidemic, President Obama's National HIV/AIDS Strategy envisioned a United States in which all those living with HIV would have "unfettered access to high-quality, life-extending care, free from stigma and discrimination."¹

This issue of *Perspectives* explores HIV-related stigma, how it has manifested over time, and how it continues to thwart efforts to prevent and treat HIV disease. It then discusses how public health addresses stigma at the policy level, and what individual counselors can do to assess for and respond to HIV stigma in the counseling session.

What Is Stigma?

The word "stigma" comes from the Greek term for a mark that was cut or burned into a person's skin to brand them as a criminal, slave, or traitor.² This disfiguring sign would shame the marked individual and warn anyone who might interact with the person to avoid them.

In 1963, sociologist Erving Goffman said that the consequences of living with stigma included "being reduced from a whole, usual person to a tainted, discounted one." This "spoiled identity" included being viewed negatively by and cut off from others in the community, sometimes permanently.³

The experience of stigma is not just social, but also personal. Medical sociologist Graham Scambler has described two different kinds of stigma. "Enacted stigma occurs externally, and is the result of actual judgment, mistreatment, and discrimination of the stigmatized person by others. "Felt" stigma (or "perceived" stigma) is the fear of such mistreatment.⁴ A third kind, "self" stigma, occurs when the stigmatized person turns harmful judgments on themselves (as with shame and guilt). "Felt" and "self" stigma affect the person internally, and may or may not be related to their own experiences of enacted stigma in the past. At times an individual may experience both internal and external stigma, or either one separately.⁵ People who have medical conditions that are highly stigmatized are likely to try to conceal their diagnoses.⁶ Even if they are successful, thus preventing outright discrimination, the experience of fear and hiding can threaten self-esteem and identity, and disrupt the person's life.⁶ Figure 1 below shows some of the ways that both internal and external HIV stigma can manifest, and the effects that both of these can have on the person living with HIV.

Some Historical Background

Many diseases—including mental illness, cancer, tuberculosis, and a variety of sexually transmitted diseases—carry stigma, so what makes HIV so special? Theodore de Bruyn has identified five aspects of HIV that have made it particularly stigmatizing:

- It is life-threatening
- People are afraid of contracting it
- It is associated with behaviors that are already stigmatized themselves—including gay sex and injection drug use

External HIV-related stigma

Attitudes or actions expressed toward people living with HIV/AIDS

- Rejection
- Avoidance
- Intolerance
- Stereotyping
- Judgmental attitudes
- Discrimination
- Disrespect
- Physical violence
- Verbal derision
- Lack of HIV transmission knowledge leading to unfounded fear of infection

Internal HIV-related stigma

Feelings, beliefs, or actions within or instigated by the person living with HIV/AIDS

- Shame
- Self-blame
- Secrecy related to fear of disclosure
- Despair
- Great concern over the thoughts and attitudes of others

Consequences of HIV-related Stigma

- Mental health issues
- Medication adherence issues
- Problems accessing health care services
- Employment issues
- Housing issues
- Risk for physical violence and/or verbal abuse

guished between “innocent” victims—like infants or hemophiliacs—and people who acquired the disease sexually or through drug use. Further reinforcing the idea that HIV was a problem for “other

people,” who are “not like us”:

Until January 2010, a 22-year ban kept non-U.S. citizens living with HIV from entering the United States unless they had a special waiver.⁸ As epidemiologist Thomas Coates put it, such restrictions give the public “a false sense of security” without conferring any real safety.⁸

Partly in response to horrific experiences of discrimination and mistreatment, legislatures and courts created a range of HIV-related legal protections, including requirements around consent for testing and confidentiality of HIV status. Yet it was not until 2008 that amendments to the Americans with Disabilities Act of 1990 clarified that discrimination against people living with HIV

(whether they had symptoms or not) was illegal under federal law.⁹

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“In the fight against HIV, stigma and complacency” remain “among our most insidious opponents,” Kevin Fenton, CDC’s then-director of the National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, said last year. Although knowledge, attitudes, and public policies have changed significantly over the past 30 years, stigma is still evident among individuals, communities, and society at large. Here are a few examples:

Ignorance, Discomfort, and Blame.

A 2012 Kaiser Family Foundation poll of more than 1,500 U.S. adults found progress away from stigma has been “slow” even if it is “steady.” One-third of the respondents in last year’s poll said that, “In general, it is people’s own fault if they get AIDS.” Twenty-one percent of respondents said “I sometimes think that AIDS is a punishment for the decline in moral standards.” Twenty-seven percent of respondents believed that HIV could be transmitted through sharing a drinking glass, 17 percent through touching a toilet seat, and 11 percent through swimming in the same pool as someone living with HIV.²¹ These judgments and incorrect perceptions contribute to a lack of comfort with HIV-positive people as co-workers, roommates, teachers, and food service workers. These findings echoed an earlier study by the American Foundation for AIDS Research (AmFAR), which reported in 2008 that more than half of the nearly 5,000 respondents surveyed would not want to have an HIV-positive woman as a physician, dentist, or childcare provider, and only

Adapted from Florum-Smith JL, deSantis JP. Exploring the concept of HIV-related stigma. *Nursing Forum*. Volume 47, number 3, July–Sept 2012. Pp 153–165 [1] Scambler G. Stigma and disease: Changing paradigms. *The Lancet*. Sept 26, 1998, p. 1054–1055.

- People living with HIV are often blamed for getting the disease
- Some people believe that having HIV is the result of a moral failing that deserves punishment⁷

Earlier in the epidemic, widespread ignorance and fear about how HIV was transmitted, and the lack of effective treatment also fueled HIV-related stigma.

On an individual and community level, people living with HIV were often rejected by family, friends, and churches, and suffered from violence and harassment. On an institutional level, it was common for people to lose jobs, or be denied certain health services, or for children to be turned away from schools. On a societal level, messages in the media distin-

15 percent thought that HIV-positive women should have children (as compared with 59 percent for women with cancer, 37 percent for multiple sclerosis, and 20 percent for hepatitis C).¹⁰ This suggests that many are unaware that effective treatments can prevent HIV-transmission from mother to child in nearly every case, and that life expectancies for people with HIV are similar to people without HIV.

Compound Stigma. Many groups most affected by HIV stigma are already marginalized—men who have sex with men, people of color, injection drug users, sex workers, poor people, immigrants, and transgender people. Some belong to many of these communities, and having “multiple characteristics that are devalued by society” increases the impact of stigma.¹¹ Multiple layers of prejudice increase the chances of victimization, and also make “coming out” as HIV-positive (or even testing) more difficult. For example, some Black and Latino men, who are already subject to racism, may find it more difficult to identify as gay, and may not participate in interventions that are targeted toward “gay communities.”⁵ Members of already-stigmatized groups may also be more aware of and sensitive to HIV-related stigma. In a 2012 Kaiser Family Foundation pPoll, 48 percent of Black respondents said there was “a lot” of discrimination against people with HIV in the United States today, compared to 39 percent of Latino respondents, and 38 percent of White respondents.¹²

Compound stigma can also divide already-marginalized groups of people. For example, the Seropositive Urban Men’s Study reported in 2006 that its HIV-positive gay male participants had experienced rejection,

discrimination, social isolation and avoidance, judgmental attitudes, and fear of infection from HIV-negative men in the community. As a result, many feared and ultimately avoided disclosing their status, and sometimes chose to live more isolated lives rather than experience such rejection again.^{5,13}

Sexual Stigma. The potential for sexual rejection exists in communities of every sexual orientation. Within the gay male community in particular, it is common for marginalizing comments about HIV status to appear in online personal ads or other postings. Ads that say “HIV-Neg—UB2” can painfully reject potential sexual partners who know that they are positive without any further discussion. However, without further discussion, it’s hard to know whether a man who responds to the posting has actually been tested, or how recently. Fear of sexual rejection may cause some people to choose not to find out their status, or not to share it.¹⁰

Criminalization. Thirty-two states, including California, have some law that criminalizes the transmission of HIV (or even potentially exposing someone to it). California’s law is more focused than many others, because it requires that the individual know his or her positive status, fail to inform sexual partners, not use condoms for anal or vaginal sex, and have a *specific intent* to infect the partner. In some other states, activities that cannot transmit HIV are criminalized (for example, an HIV-positive man in Texas is serving 35 years in prison for spitting at a police officer).¹⁴ HIV itself is often associated with behaviors that are illegal in many countries: sex work, gay sex, and injection drug

use,¹⁵ and criminalizing acts that could (and in some cases, could not) transmit HIV strengthens the association that HIV-positive people are dangerous criminals, increasing stigma. Earlier this year, the Presidential Advisory Council on HIV/AIDS called for an end to HIV-specific criminal laws, saying, “HIV criminalization is unjust, bad public health policy and is fueling the epidemic rather than reducing it.”¹⁶

Syringe access still under fire.

Decades after syringe access has been proven effective as a harm reduction strategy, there is once again a ban on using federal monies (such as Centers for Disease Control and Prevention funding) to help provide clean syringes. Although California state law still allows both syringe exchange programs (SEPs) and nonprescription sale of syringes (NPSS) in pharmacies,¹⁷ Congress reinstated the federal funding ban in 2011 after about a year of its being repealed. The argument against encouraging needle exchange and syringe access programs is often that it encourages drug use by reducing the fear of harms (such as HIV and hepatitis C) that can happen through use. This is despite significant, long-term evidence that led then-Secretary of Health and Human Services Donna Shalala to say in 1998: “A meticulous scientific review has now proven that needle exchange programs can reduce the transmission of HIV and save lives without losing ground in the battle against illegal drugs.”¹⁸

How Stigma Fuels the Epidemic

Stigma around HIV disease helps propel the epidemic in several ways. The Treatment Cascade (see the graphic below) illustrates the steps

necessary for HIV-positive people to achieve an undetectable viral load that can lead to better health outcomes, as well as reducing the possibility of transmission. It also highlights the places where people can be lost to the successful treatment that is necessary to achieve an undetectable viral load.

Several studies over time and around the world have found that stigma can play a role in avoidance of HIV testing.^{19,20,21,22} When individuals who are HIV-positive, but do not yet know their status delay testing, the opportunities to link them to HIV-specific treatment and care, to notify and test their partners through Partner Services, and for the HIV-positive individuals to change their behavior in light of knowing their status are all lost.

Fear of stigma impedes honest discussion of HIV prevention or status disclosure with sexual or needle sharing partners, particularly if there is a concern that such discussion would lead to social or sexual rejection or violence. The desire to avoid such discussions may also be an obstacle

to using condoms or other forms of harm reduction. A study of 170 HIV-positive gay, bisexual, and transgender people of Latin American descent in Chicago and San Francisco reported in 2013 that experiences of enacted stigma were “negatively associated with self-esteem, social support, and safe sex self-efficacy.” Having experienced stigma in a romantic or sexual context was strongly associated with substance use.²³ A study of 637 homeless or unstably housed HIV-positive people in Chicago, San Francisco, and Baltimore reported in 2009 that perceptions of external stigma were associated with lower HIV disclosure to friends, family, and acquaintances, while internalized stigma was associated with substance use and non-disclosure of status to sexual partners.²⁴

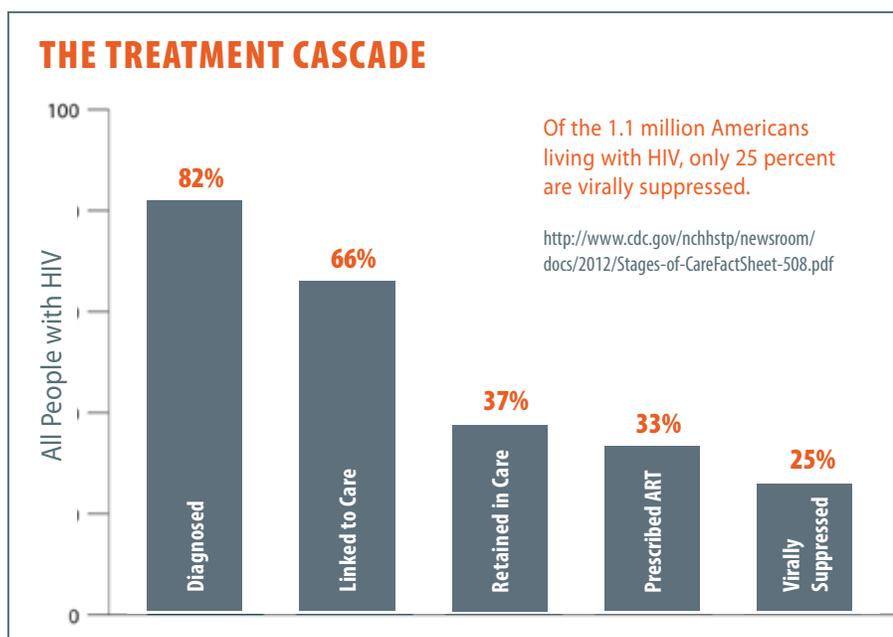
Receiving medical treatment can minimize or eliminate the visible effects of any opportunistic infections or immune damage an HIV-positive person experiences. However, fears about stigma as a result of being seen accessing care, being seen taking antiretroviral medication, or concerns

about the visible effects of antiretroviral therapy (such as fat redistribution in the face and body, called “lipodystrophy”²⁵) can all cause people living with HIV to delay beginning treatment or not adhere to treatment. One 2006 study of 221 HIV-positive men and women who were outpatients of a clinic in Central New York State found that experiences of stigma were significantly related to non-adherence to medications, as well as to missed appointments at the clinic.²⁶ A 2009 study of nearly 968 HIV-positive adults in San Francisco, Los Angeles, Milwaukee, and New York City reported that African American respondents were nearly twice as likely to report wanting to hide their HIV status as non-Black participants.²⁷

When people who are living with HIV do not access treatment services fully and consistently, they lose the opportunity to arrest the progress of the disease in themselves, and their partners miss out on the benefits of treatment as prevention (the fact that undetectable viral loads in HIV-positive people are associated with greatly reduced transmission of HIV to others). Despite ADA protection covering workers in many situations, employees who fear repercussions at work may hesitate to ask for accommodations (including taking sick time for medical appointments). Because stigma can play a role in interrupting the Treatment Cascade at every step, reducing stigma is an important priority of prevention and care efforts.

What’s Being Done

Several initiatives seeking to minimize the harmful impact of HIV stigma in the United States are under way. These include:



Media Campaigns like the Centers for Disease Control and Prevention's "Let's Stop HIV Together" effort, using images of people living with HIV along with friends, partners, and family members. The message is one of connection between HIV-positive and HIV-negative people, and shared responsibility in ending the epidemic. (http://www.cdc.gov/actagainstaids/together/pdf/Poster_Erica.pdf)

Similarly, The Stigma Project (<http://www.thestigma.org>) uses social media and advertising to promote the message "Live HIV Neutral" by educating both HIV-positive and HIV-negative people about the harm of HIV stigma. The site's "HIV Talk" highlights examples of hurtful remarks that stigmatize HIV-positive people, and offers alternatives. (See "Dating Etiquette and HIV," Page 7). The Canadian website www.hivstigma.com focuses on reducing HIV-related stigma within gay men's communities, and notes how gossiping about a person's status, making judgments about men living with HIV (including that younger ones "should have known better"), discourage people from testing, disclosure, and treatment, ultimately putting the community at greater risk.

Emphasis on Linkage Services. Services for HIV-positive people that emphasize linkage to care and other supportive services that help maintain treatment adherence not only improve health but also help combat the isolation many people experience when they are diagnosed. People living with HIV may experience a new sense of community through involvement with peers and care providers whose goal is to help maintain their health and well-being.

Treatment Education. As the public becomes better informed about vast treatment advances, which make HIV less "life-threatening," fears are quelled. Milestone findings about the effectiveness of such strategies as "treatment as prevention" reduce fears around both the contagiousness and fatality of HIV.

Universal Testing. It is believed that making HIV testing a regular part of medical care will reduce stigma around testing, since all patients should be tested at least once—regardless of their sexual or drug-using behaviors.²⁸ The recent approval of an over-the-counter rapid HIV test (the OraQuick In-Home HIV Test) that people can administer and read themselves offers

What Counselors Can Do

Many interventions to reduce HIV stigma must occur at the community and societal level. But counselors can also lessen the impact of stigma on our clients in several ways:

Remember that information alone does not lead to behavior change. We may find that we sometimes blame clients for engaging in "risky behavior" even though they "know better," and it is important to stop and examine these beliefs.

Think about the context, and then notice whether stigma is part of that context. Clients experiencing HIV-related stigma may have anxiety and depression, and may increase their use of substances in order to cope.^{25,31}

Because stigma can play a role in interrupting the Treatment Cascade at every step, reducing stigma is an important priority of prevention and care efforts.

another option for individuals to learn their status in a private setting.²⁹

Access to Care. The more options that HIV-positive people have for quality health care, the more likely they are to access care and adhere to treatment. Finding and keeping medical insurance coverage has been especially difficult for people living with HIV, so it is not surprising that only 17 percent of HIV-positive people have private health insurance, and 30 percent have no health coverage at all. Under the Affordable Care Act, insurers can no longer deny coverage to people (or set their premium prices) based upon preexisting conditions such as HIV disease, place a lifetime cap on benefits, or impose annual limits on coverage.³⁰

Maintain your neutral stance. Modeling non-judgment is key to creating a less stigmatizing climate for the client. Avoid loaded terms—like "contaminated" or "clean" (to refer to people or HIV status) or even "infected" or "risky" if another word (like "HIV-positive" or "higher chance of getting HIV") will do.

Listen for signs of stigma in the session. Clients may be reluctant to test or concerned about confidentiality of results; not have told anyone they are testing; say that they don't know how they would tell people if they had HIV, or couldn't handle knowing themselves. They may talk about family or community rejection due to drug use or sexual orientation, or negative experiences of family members

or friends who tested HIV-positive. Some clients express that it is “only a matter of time” before they get HIV because they are gay or use drugs. Clients who test positive may express reluctance to enter medical services.

Use client-centered counseling techniques. Let clients know that they are not alone in their experiences. When a client expresses feeling ashamed, “dirty,” or rejected,

the counselor can *normalize* these feelings: “Yes, that’s normal to have those feelings, even if you have nothing to feel ashamed of.” Or the counselor can use *third-personing*: “Many of my clients tell me that they have felt that way in this situation. They also tell me that those feelings usually pass with time.”

Gently point out assumptions and contradictions. Many people

who would refuse to have sex with an openly HIV-positive partner also feel safe having sex without any discussion of HIV status. Counselors can use double-sided reflections like “On the one hand, you are trying to protect yourself from HIV by not having sex with guys who have been tested and have disclosed to you that they are positive. On the other hand, the topic only comes up about a third of

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the time you have sex. What is helping you feel protected the other two-thirds of the time?” This gives clients a chance to explore their assumptions about status, and to realize that they are likely having sex with partners of opposite HIV-status, but by refusing to discuss it, are missing out on opportunities to avoid transmission.

Explore non-stigmatizing communication. Counselors can help clients think about ways that they could talk with partners about HIV status and prevention without stigmatizing their partners. This includes encouraging empathy—how would your client want to be treated if he or she were disclosing a positive HIV status? The Stigma Project has suggested that HIV-negative people looking online for sexual partners use clear, neutral language to share their status with others and begin the conversation about HIV prevention.

Offer resources to continue the conversation, and emphasize confidentiality. Part of helping clients feel less isolated is connecting them to appropriate referrals in the community. For clients who test HIV-positive, standard referrals include linkage to HIV-specific medical care, Partner Services, and sometimes case management. If you live in an area where some

form of HIV-positive peer support is available to clients, offer this as well. Help clients troubleshoot the ways that stigma could sabotage their care. You might ask, “Where would you feel most comfortable receiving care?” Some clients may want to receive services in their own community, while others may want to go outside it. Emphasize the ways in which medical care is confidential, and that Partner Services is anonymous—this may reassure clients who are concerned about HIV-related stigma.

Conclusion

Despite major advances in HIV treatment, and in education of the public, stigma continues to be a significant obstacle to HIV prevention and treatment, impacting the Treatment Cascade at every level. The ways that HIV-related stigma manifests in the United States continue to change over time, and HIV test counselors are on the front lines of the personal and public health response that can counter its destructive effects. ■

DATING PROFILES & HIV CHEAT SHEET

LANGUAGE YOU SHOULD ADJUST IF YOU WANT TO **AVOID CONFUSION** OR **REDUCE STIGMA** AROUND HIV WITH YOUR POTENTIAL DATING OR SEX PARTNERS.

AVOID	SAY
<p>“CLEAN” WHEN REFERRING TO HIV, IMPLIES THOSE WHO ARE POSITIVE ARE DIRTY OR UNCLEAN. “CLEAN” ALSO CAUSES A LACK OF CLARITY WITHIN THE CONVERSATION BECAUSE THE TERM HAS MANY DIFFERENT CONNOTATIONS.</p>	<p>“NEG, TESTED ON [INSERT DATE].” KEEP IT UPDATED. IF SEXUALLY ACTIVE YOU SHOULD GET TESTED EVERY 3 MONTHS. IF YOU FEEL LIKE YOUR TESTING DATE SHOULD REMAIN PRIVATE, AT LEAST PROVIDE A GENERAL TIME FRAME SO THE POTENTIAL PARTNER CAN PROPERLY ASSESS THEIR RISK.</p>
<p>“DRUG & DISEASE FREE” or “DDF” SUGGESTS THE TWO ARE MUTUALLY INCLUSIVE AND THAT PEOPLE WITH HIV ALSO USE DRUGS.</p>	
<p>“NEG ONLY” DISCOURAGES PEOPLE FROM GETTING TESTED AND DIMINISHES THE ESTEEM OF THOSE WHO ARE POSITIVE. IT ALSO ENDS THE CONVERSATION BEFORE IT SHOULD BEGIN.</p>	

<http://www.thestigmaproject.org/#untitled/zoom/c1hllimage1pjb>

IT'S EASY TO FORGET ABOUT THE PEOPLE AFFECTED BY OUR WORD CHOICES WHEN WE NEVER SEE THEM FACE-TO-FACE. WE HIDE BEHIND OUR SCREENS AND PAY NO MIND TO HOW OUR LANGUAGE MAY OFFEND, DEGRADE, OR HURT AN ENTIRE COMMUNITY.

THESTIGMAPROJECT

Test Yourself

Review Questions

- True or False:** Even though it existed in the past, it is safe to say that HIV stigma is almost nonexistent today.
- Name three kinds of stigma that are discussed in the article: a) “enacted,” “reactive,” and “self;” b) “enacted,” “felt,” and “self;” c) “enacted,” “self,” and “fear-based;” d) “enacted,” “self,” and “other.”
- True or False:** “Enacted” stigma is the fear of mistreatment by others.
- In a 2012 Kaiser Family Foundation poll, what percentage of respondents agreed with the statement: “In general, it is people’s own fault if they get AIDS”? a) 15%; b) 26%; c) 33%; d) 48%.
- According to the article, the reasons that HIV has been so stigmatized include: a) it is painful; b) it is associated with behaviors like sex and drugs; c) people are afraid of transmitting it; d) all of the above.
- HIV-related stigma interrupts the Treatment Cascade because people who fear stigma may be: a) afraid to test; b) reluctant to disclose their HIV-positive status; c) inclined to avoid HIV-related medical treatment; d) all of the above.
- The article discussed some ways that HIV-related stigma can show up in online postings for sexual and dating partners. Which of the following postings is less stigmatizing than

the others? a) “HIV-Neg, UB2”; b) “DDF”; c) “Neg, tested 10/15/13”; d) “Clean—Neg Only.”

Discussion Questions

- How do you notice that clients are letting you know that stigma is playing a role in their lives and putting them at risk for HIV?
- What are some ways to respond to clients who say that stigma keeps them from talking about HIV-status with partners?
- How might you address the stigma-related concerns of a client who tests preliminary positive or positive? What strategies would you use to help support them and keep them connected to care?

Answers

- False. HIV-related stigma still exists today, and its manifestations are discussed in the article.
- b.
- False. “Enacted” stigma is the result of actual judgment, mistreatment, and discrimination of the stigmatized person by others.
- c.
- d.
- b.
- c.



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