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Article

"They Have always Called Us Sick: Heterosexism and Medical Inequality for Queer Americans with Chronic Illness and a Potential New Direction for AIDS Discourses"

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Abstract: HIV/AIDS and COVID-19 discourses are often compared; however, theorizing them together in terms of political efficacy and possibility is more novel. The collective of academics, activists, artists, and others—What Would an HIV Doula Do? (WWHIVDD) which for years has responded to the HIV/AIDS pandemic, has turned their attention to experiences of living with COVID-19. Through a qualitative analysis of two texts—a zine and a guide for authors writing about these pandemics—that specifically address experiences of/with COVID-19 by WWHIVDD, we examine how HIV/AIDS and COVID-19 discourses can productively be considered as chronic illness/COVID discourses that have the potential for more fruitful collective/political action and scholarly theorization of people living with pandemics.

Keywords: queer theory; pandemics; sexuality; AIDS discourses; COVID discourses

Introduction

In this article, we theorize how narrative discourses, studies of queer people, and people living with HIV/AIDS (specifically in terms of AIDS discourses) intersects with and also informs long COVID discourses' understandings of care and treatment for marginalized individuals living with chronic illness (Smetalan et al, 2021). While critical studies of long covid have compared HIV and Covid-19 narratives and discourses (e.g. the special issue "Viral times: Rethinking HIV and COVID-19 in the journal *Culture, Health, & Sexuality*), we seek to gain greater understanding of experiences at the intersections of these pandemics. The work of Cohen and van der Meulen Rodgers (2023) and Devoto (2023) approach long Covid through a lens of intersectionality but do not center queer voices within their analyses. Building on Mackenzie's (2022) analysis of health organizations that through an affective quality that links HIV/AIDS and COVID-19 discourses as what she terms "an integrated health social movement," we hope to more closely analyze texts that center queer folk living with long COVID. Through analysis of these texts we begin to theorize pandemic discourses in a way that resists the neoliberal and hegemonic forces that contribute to binary and limited conceptualizations of those living with pandemics that are now more understood as chronic illness. People living with long Covid have a unique epistemic knowledge because "it is the first illness to be made through patients finding one another on Twitter and social media" (Callard & Perego, 2021); they describe the illness as one that is patient-made and like HIV/AIDS patients of the past patients developed authority to establish credibility and challenge assumptions and misunderstandings of their respective conditions.

Our article is informed by recent analysis of patient narratives of long Covid (Rushforth et al, 2021; Cheston et al., 2023; and Miyake and Martin, 2021) which frame patient narratives in terms of ideas of temporality, language, and related concepts. Much critical work also relates current pandemic concerns with the seminal work of social historian Charles Rosenberg whose theory of

epidemics locates epidemics as social and cultural events that also mirror dramas. Within these theoretical frameworks, through a closer reading of texts from queer voices living with/amongst Long Covid, we hope to highlight how the epistemic understanding from these intersections can provide fruitful theorization for the practice and study of patients living with epidemics/pandemics/chronic illness.

Queer communities have been dealing with the stigma of long-term illness since “homosexuality” was first criminalized by Paragraph 175 in the penal code of the Germanic states in 1871 (Jagose 2008). Michel Foucault (*passim*) argues that at the moment an identity becomes crystalized, or concretized, and is defined by hegemonic discourses as “abnormal” or “deviant,” that identity becomes understood by those defined as “normal” by juxtaposition as a disease itself where “normal” or “average” is also understood as “healthy.” Renowned social psychologist, Erving Goffman (1986) broke down all identities as being either Discreditable or Discredited when it came to the application of stigma to any given identity. Risking oversimplification in the interest of brevity, Goffman’s main point is that everyone has at least a potentially stigmatized identity were the discreditable parts of self ever exposed to the world; thus, stigmatizing anyone is a matter of social prejudice and not just moral judgment. A diseased identity is a stigmatized identity. Community can break down in the face of even just perceived communicable illness. Communities can also be built around shared stigmatized identities. The invisibility of some diseases that are also stigmatized and associated with minoritized identities broadens the stigma of the disease to the entire minoritized communities.

Coming out of Queer Theory, AIDS discourses were a direct response to the HIV/AIDS crisis of the 1970’s through the 1990’s around the world and especially spurred on by the malignant neglect of the Reagan and Thatcher Administrations of the 1980’s US and England (Bronski 2011). There are many multi-dimensional and intersectional aspects to AIDS discourses, but for the purposes of our article, we will be focusing on the efficacy of AIDS discourses to de-concretize the liminality of identities by pointing out that HIV, the virus that leads to the condition AIDS, is connected with risky sexual behaviors, not sexual identities. Many straight Americans and English (and really straight people around the Anglophone world) “jokingly” called HIV/AIDS “the gay flu” even after straight-identifying people started coming out as HIV positive. Despite straight-identifying African American women having the fastest growing population of HIV-positive people, HIV/AIDS are still thought of as “gay diseases.” This false association between disease and social identity not only hurts queer communities, but straight ones too. Not many outside of groups and scholars involved in AIDS discourses and/or medicine to some degree even know that it is a straight-identifying group that has the fastest growing numbers of HIV infection. The lack of awareness means what it has historically always meant for Black women in lower socio-economic statuses (SES) in the US—less attention to the problem, less help, fewer resources, less research, and higher mortality rate.

AIDS discourses have always been about carrying through on the poststructural project in Queer Theory of deconstructing the boundaries of identity through the epistemological implosion of meaning. The poststructuralist project, the anti-enlightenment project so to speak, was always an attempt to deconstruct identity itself due to its divisive nature. Younger generations, as a trend, rejecting labels is one example of the expression of Poststructuralism in the construction of self in nation-states that have made the “postmodern cultural turn” in late-stage capitalistic economies (Jameson 1998). Our article is the first, to our awareness, to argue that COVID discourses may be more effective in Queer Theory to achieve the intersectional understandings and focus on social behaviors rather than social identity AIDS discourses attempted to bring to mainstream awareness. To be clear, this is not intended as an attack on AIDS discourses or their importance, but an attempt to answer the question, how do we keep Queer Theory queer once it has become a normative academic discourse?

For the past 30 or so years, queer theorists have been asking and attempting to answer the question of what does post-queer look like? Turning to one of the founders of Queer Theory, Michel Foucault, we already have a roadmap. Post-queer is pre-queer. That is to say, post-queer is post-sexual identity and a return to thinking about sex in terms of desire and behavior instead of social

identity. We do not even have to go back very far in history to find the times before sexuality. There is some historical debate, but generally the first uses of “homosexuality” in political-legal discourse was Germany in 1869 but defined by scientists in the 1890’s. COVID discourses, adapted to Queer Theory, might be a more effective way of raising broader awareness of the multi-dimensionality of disease, especially invisible disease, identity groups, and social behaviors and desires without the baggage of pre-existing stigmas.

Theoretical and Historical Connections

As briefly mentioned in the introduction, the question of long-term illness is a complicated one for queer communities. Despite the presentism and ethnocentrism of some historians and anthropologists, sexuality as a distinct social identity did not exist until the 19th century in Western Europe and the US. Prior to the creation of sexuality, people were described and understood according to sexual behaviors, but that did not translate into concretized identity positions. To put the point bluntly, just because ancient Athenian male citizens thought that sex and love between men were the highest expressions of both does not mean ancient Athenian male citizens were “gay” or “homosexual.” The concept “gay” and its contemporary meanings regarding sexuality did not begin until the 1920’s US. Ancient humans understood sex as something a person does, not something someone was. This is an important point for readers not already familiar to understand; the use of sexual identity as a way of defining self, regardless of what sexual identity, is, in the scope of things, still a very new social construction (Lehring 2003; Foucault 1990; Halperin 2013; Boswell 1995; Bronski 2011). Even the term “homosexual” can only be dated to late middle 19th century in the Germanic states.

The socio-history of the term, “homosexual,” is important because the concept was always intended to describe a disease. The history of the term fits the model of discursively delimiting and then eliminating those defined as “other” outlined in Foucault’s lectures at the Collège de France between 1974 and 75 titled, “Abnormal” (Foucault 2003). In the beginning, there was the monster. The figure of the monster belongs to ancient mythos. It is the embodiment of madness, sacrilegious admixture of human and other animal, a combination of different animals, violations of “natural order,” mixtures of culturally defined opposites (like life and death or men and women in the case of “hermaphrodites,” known as intersex people today), and/or mixtures of things that are so similar and spiritually powerful, they could damage the fabric of the cosmos if they ever met. In Nietzschean terms, it is embracing the madness of Dionysus over the rationality of Apollo that creates the monster. Dionysus, with his retinue including the ever-erect satyr Pan and the fat, happy, wise, and drunken god Silenus, represented the other. Even the Greeks of Socrates’ time referred to Dionysus as “the foreign god” even though he had been worshiped in that part of the Mediterranean world since the Mycenaeans. The monster is feared, ostracized, hunted, revered, normal (at times, even hegemonic—such as Senator Joseph McCarthy convincing so many Americans into seeing monstrous “commies” everywhere), murdered, and worshiped. To say the monster occupied an ambiguous place in ancient and contemporary cultures would be an understatement.

Sexual behavior was not inherent in the figure of the monstrous, but it did occasionally factor in for ancient Greeks and Romans, often as sexual assault, instead of consensual sexual behavior, especially against women, such as Aphrodite’s punishment of Medusa for being raped by Poseidon in her temple. Another example, in the *Torah*, in the book of *Leviticus* (a favorite from which evangelical Christians often like to cherry-pick), where a man lying with another man as a woman is described as an “abomination” (Helminiak 2000). Women lying with other women was frowned upon but ultimately seen as the fault of men in the same book. According to theologian, Daniel A. Helminiak (2000), men were seen by ancient Hebrews as being imbued with high levels of spiritual power, which they must use part of to create new life inside of women as incubators. The word, “abomination” fits Foucault’s definition of the monster- it is an admixture of things that are opposites or too powerful and similar to be put together (thus the prohibition against eating shellfish in Judaism as an unholy mixture of fish and animal). Thus, in the cultural logic of ancient, tribalistic, nomadic Israel, men mixing their spiritual powers through sex could cause such a concentration of power that

it challenges the nature of reality and leads to plagues and cataclysms like earthquakes, or as Jerry Falwell claimed, Hurricane Katrina.

The next figure in the development of the sick and criminal abnormal type, can be dated to 18th century European and Utilitarian (such as Jeremy Bentham) thought emerging out of the combination of judicial and medical discourses that led to the reorganization of hospitals and prisons along the same logic for both. The sick and the criminal, if they refused to “improve,” were the “incurrigibles.” They were in need of correction and yet incapable of being corrected. The incurrigible emerges from the European Enlightenment myth. The only answer was either the “leprosy model” of ostracization but with the gain of community in the Lepers’ colonies or the “plague model” of internalized shame, repentance for sins that caused the infliction, and acceptance that the disease or criminal penalty was a just punishment handed down from one of the Christian gods. That the US still has the death penalty, the possible sentence of lifetime imprisonment without possibility of parole, or involuntary, indeterminate imprisonment in a psychiatric hospital are testaments to the continued belief in the incurrigible (Foucault 2003).

The final piece to the genealogy of contemporary abnormality develops in the Victorian era and is the onanist, the chronic masturbator. Coming from the story in the *Torah* about Onan, the onanist as a figure is the sexual deviant and adds the element of sexual behavior and identity into the contemporary definition of “the abnormal.” The onanist lacks self-control and is thus a threat to itself and others. It is a threat to normative, heteronormative, that is, society. By the 20th century abnormality had elements of the monster, the incurrigible, and the onanist wrapped into one figure in politico-judicial-medical discourses to terrify the *hoi polloi*. The abnormal acts as a form of social control not only on those labeled abnormal, but by example, as a form of social control on those define as “good, upstanding citizens” (Foucault 2003).

The above is to set the sociological context for the social history of homosexuality as a disease that then linked with other diseases, such as HIV or Monkey Pox (MPox). Turning our attention to the role of law and criminalizing the “disease of homosexuality,” Paragraph 175 of the German penal code comes back into the story. After the unification of Germany under Otto von Bismark in 1871, the German Penal Code solidified the legal institutionalization of Paragraph 175 that outlawed for the first time anywhere in the world being homosexual as an identity and a social threat. With the fall of the Weimar Republic and the rise of Hitler and the Nazis, Paragraph 175 was a useful law that empowered the Gestapo to round up all suspected of homosexuality and force them into the concentration camps wearing, not golden Stars of David, but pink triangles. When Allied forces liberated the Nazi concentration camps, those wearing pink triangles were re-imprisoned under the same Paragraph 175. The American Psychological Association publishes the Diagnostic and Statistical Manual for abnormal psychology (the DSM). Until 1973, when the DSM-IV was published, homosexuality was listed as a mental illness and the DSM, as an expression of Foucauldian biopower, was used as the justification for locking up anyone “diagnosed” with homosexuality in psychiatric hospitals (Foucault 2000).

Across the US, state and city laws were passed linking homosexuality with communism, criminality, disease, pedophilia, necrophilia, murder, psychopathy, and vagrancy. Police were empowered in most jurisdictions to charge people with lewd acts, vagrancy, and pedophilia if the officer just suspected a person in a public area with children nearby to be homosexual (Bronski 2011; Mogul, et al. 2011; Brooks 2015; Jagose 2008). Courts were not sympathetic to those accused of homosexuality and often remanded convicted “offenders” to psychiatric hospitals where Aversion Therapy was used to “cure the gay.” Such treatments included electro-shock treatment to different body parts, including genitalia, while exposing prisoners to same-sex pornography, the use of chemicals to simulate waterboarding (“Advanced Interrogating” the gay away), and for the most incurrigible cases, icepick lobotomies were the order of the day. Stays in such hospitals often resulted in either no change, the reported destruction of people’s libidos altogether, or in need of life-long medical care due to the side effects of lobotomies (*Ibid.*).

The preceding social history is a short summary of what could easily fill books, but the history is presented here to establish the judicial-medical discourses discussed by Foucault, and to set the

context for the emergence of the HIV/AIDS crisis created a new way of pathologizing LGBTQ identities while pretending that second-class citizenship was justified by the presence of HIV/AIDS just as psychologists removed homosexuality as a mental illness with the publication of the DSM-IV in 1973. With great public awareness coupled with high levels of ignorance regarding the virus, HIV came to be understood by those outside of medical and LGBTQ communities as something that defined queer existence. AIDS discourses pointed out repeatedly how HIV was inherently queer in that it had no respect for social boundaries of identity. AIDS discourses have always been intersectional and multi-dimensional, but its continued association in straight communities as a “gay disease” not only ignores facts like of all sexual identities, those who identify as lesbian are the least likely group to contract HIV due to differences in common sexual practices. For lesbians, breast cancer would be a far more important medical issue than HIV.

We propose COVID discourses or chronic illness discourses as a new way to talk about the queerness of disease without the heterosexist framing that exists to this day around HIV/AIDS. COVID broke through assumed crystalized identity groups, like the bubonic plagues of the Medieval Period, COVID affected the powerful and powerless, the rich and the poor, all races and ethnicities, all genders, and all sexualities. Pre-existing social inequalities, just as in every pandemic, worsen the effects of disease for those of lower SESs, but the social elites of a given society were not, *de facto*, safe from infection and possible death. The qualitative data analyzed for our article has revealed very little substantial difference between queer voices on experiences of COVID and non-queer voices. People whose lives have been affected by COVID focus on the need for greater resources, community support, and intersectional coalition building. These initial finding offer support to our hypothesis that COVID or chronic illness discourses may be more effective in breaking down assumed crystalized identities. Another way to say the same is that we should embrace COVID in Queer Theory as an inherently queer disease and a tool to increase social movements for improved healthcare as well as greater empathy and radical acceptance for populations that have for so long been defined as “other.”

Materials and Methods

Queer patterns of knowing are particularly salient within the COVIDicene (Brown et al., 2022) which exposes the epistemological and ontological limitations of the Anthropocene. As Ebru Yetiskin (2022) notes the pandemic “has been predominantly embedded within biopower” which demonstrates control mechanisms of governments over populations. In his Foucauldian genealogical analysis of homosexual pejoratives, Ragan Fox notes how epidemics/pandemics from HIV/AIDS to MonkeyPox (MPox) have silenced minority voices. Given these dynamics an analysis of texts by “community of people joined in response to the ongoing AIDS crisis” which views members as “someone who holds space during times of transition” (HIV Doula Work) including during the COVID-19 pandemic.

We analyze two texts produced by the collective What Would an HIV Doula Do? (WWHIVDD). WWHIVDD is “a mixed HIV/sero-status, multi-racial, cross-class, intergenerational collective...across North America who have found community with...(a) shared commitment to responding to the ongoing HIV/AIDS epidemic” (Brier et al., 2023, 122). Their work “has been challenging and expanding radical care across media for years, and their work has not changed in our uncertain COVID-19 world” (Wakefield, 2022). The collective has produced a COVID-specific zine, *In our bodies: A zine about pleasure, intimacy, and reality in 2020*, and a guide for writers, “Twenty-seven questions for writers and journalists to consider when writing about COVID-19 and HIV/AIDS. These publications demonstrate how “COVID-19 has profoundly changed how we see the world, including the way we understand HIV” (Juhasz and Kerr, 2023, 126). These works allow us to explore how “COVID has queered human embodiment, “created new relationships and alliances,” and “nonnormative bodies and identities...(continue to be) positioned as less valuable, and more contagious, abject, unbounded, contaminated or expendable than others” (Lupton, 2022, 79). COVID is a useful discourse for Queer Theory generally due to its inherent queer nature in violating socially defined boundaries.

Results and Discussion

(Chronic) Illness and Stigma

In these two texts, WWHIVDD frames discourses surrounding COVID-19 and HIV/AIDS in terms of illness and stigma. In their introduction to their guide for authors writing about COVID-19 and HIV/AIDS, WWHIVDD writes “HIV has become a manageable chronic illness.” Molly M. Pearson’s entry in the zine describes her experiences with her father who lives with HIV as “learning to live with yet another virus in our lives. It is one thing to learn to live with a virus all around us, and it is another to learn to live with illness. My dad is still learning to live with chronic illness...” This framework is consistent with recent scholarship (Sematlane, et al., 2021) that allows for a conceptualization of HIV as a chronic illness where the “chronically ill person must appraise and acknowledge their changed situation as a result of the illness...” While this understanding of HIV is contested (Speakman, & Pawluch, 2021), this framing allows for consideration and theorization of HIV/AIDS discourses alongside and with COVID-19 narratives.

This potential flattening of discourses is also seen in how stigma and experiences of illness are discussed in the texts. In the introductions of both documents, WWHIVDD addresses systematic treatment of people living with chronic illness. As an example, in their introduction to their guide for authors, WWHIVDD, clearly highlights the processes of ‘othering’ that occur within health contexts. “Meanwhile, stigma, discrimination, and criminalization directed at people living with HIV continue, based on social difference, access to resources and community, and an array of ever-shifting economic circumstances. AIDS activism remains necessary, and the work of AIDS activists vital.

In the face of both HIV and the novel coronavirus, and the biased systems that exacerbate them, a multiplicity of lessons on how to live in an epidemic are needed now as much as ever” (Muhammad, 2020). The ambiguity of many chronic illnesses, especially invisible illnesses, in their legitimation as “authentic” diseases and those who live with chronic illnesses as either patients deserving of help and compassion, or somehow psychologically “abnormal” in claiming to be physically ill in the first place.

Moreover, whether we are talking about illnesses that are transmissible or not, the “diseased body” is either fetishized or stigmatized when regarded sexually. “When we’re talking about sex, sometimes we are talking about freedom—what it means to be in our bodies, free from stigma, coercion, and violence. We know that the medical industrial complex does not care for all of us equally, and that Black women (both cis and trans) have suffered beyond words at the hands of a corrupt medical system.” (WWHIVDD, introduction to Zine) Additionally, in her entry in the zine Kristy Harcourt writes, “However, cautiously one sees friends and lovers, there is the implication or threat of being called out as a slut, or irresponsible, or of unknowingly becoming a vector of illness.” These examples demonstrate that WWHIVDD recognizes the interrelationships between pandemic discourses. A large part of AIDS discourses has already done much of the intellectual labor in outlining the negotiations of relationships, sexual encounters, and illness. COVID discourses, as something still emerging, must center on this negotiation of relationships, sexuality, and social space (“don’t forget to social distance!”). We can see the cross over between queer cultures and straight cultures, if such a crude distinction can be allowed, in fetishizing pandemic lockdown sex such as the rise of both queer and straight expressions of “pandemic pornography” such as media of people engaged in various sexual acts while wearing differing levels of PPE.

This recognition that inequities for people living with chronic illness based on class, race, socioeconomic status, race, and other identity categories exist is consistent with recent scholarship on (Long) Covid patients. Cohen and van der Meulen Rodgers (2023) note that the “systematic barriers that affect” health outcomes of marginalized groups are also evident in the experiences of patients with (long) Covid. In their analysis of digital narratives of people living with long Covid, Rushforth et al (2021) found connections related to collective advocacy and experiences of gaslighting in narratives of patients with other chronic conditions. Devoto (2023, 527) suggests that in recognizing these overlapping instances of inequality across conditions related to chronic pain that centers the

perspective of marginalized people can be productive for both researchers and “cross-movement solidarity.”

By connecting the systematic oppressive systems experienced both by people living with HIV/AIDS and COVID-19, WWHIVDD demonstrates how drawing on cultural knowledge of living with the HIV/AIDS crisis can emphasize “the importance of intimacy and sexual expression in the face of infectious disease” (Lupton, 2022, 78). WWHIVDD’s guide for authors, includes several questions that speak to concerns regarding bias and stereotypes. They recommend a consideration of “anti-Asian stigma or stereotypes, state-sanctioned homophobia and transphobia,” the “role of sexuality, race, perceived nationality, and the history of who gets represented” when writing about illness. The process in which people experience stigma as it relates to illness is another lens where COVID/chronic illness discourses may be generative. Carmen Logie (2022, 3) suggests that an enriched understanding of stigma across health concerns can “help us to meet the immediate needs of affected communities and embark on long-term approaches to embed equity and social justice at the heart of pandemic preparedness and pandemic response.” While there are differences in how stigma may emerge within discourses, considering these processes holistically can be theoretically fruitful (e.g. Farrimond, 2023; Srivistava, 2020).

WWHIVDD texts encourage the centering of queer and specific voices and narratives but also asks us to think of these illnesses in complex interconnected ways. While this potential folding of discourses could be viewed as eliding or neglecting particular experiences, we suggest that thinking of COVID discourses that embrace and imbricate HIV/AIDS discourses can be theoretically and politically efficacious. There is particular concern for erasure of queer voices when broadening the number of groups’ voices becomes a cacophony where only the most privileged of groups are heard. This would be a move backwards for queer communities and healthcare. Instead of queer erasure, or the erasure of AIDS Discourses, we are arguing for an increase in queer representation in COVID/chronic illness discourses as we see in WWHIVDD, but also a continued deconstruction of the cultural connection between identity groups and the concepts of disease or health that we find in AIDS discourses. Together, both sets of discourses provide a powerful model to understand disease and identity. AIDS discourses provide the intellectual framework, COVID/Chronic Illness discourses provide the political battering ram to the past and current crystallization of diseases socially understood to be sectioned off by identity groups.

Conclusion

As the Roman philosopher Seneca famously wrote, “Religion is regarded by the common people as true, by the wise as false, and by the rulers as useful.” Had Seneca lived in a time with poststructuralism, he could have expanded that statement to all normative, legitimated institutions. The very concepts “disease,” “health,” “abnormal,” “normal,” have been and continue to be very true, false, and useful. As outlined above, the socio-history of the concept of “homosexuality” has, at its foundations, a plague-modeled, discourse of chronic personal and social disease (Foucault 2003). The diseased-identity discourse of mainstream cultures in the US has led the perpetual malignant neglect of queer communities’ health needs and access. Historically, AIDS discourses have tried to break the generations-long cultural association of queerness with disease. While queer theorists certainly understand the complexities, multi-dimensionality, and intersectionality of AIDS discourses as well as the important distinction between identity versus anyone engaging in risky sexual practices, mainstream, straight, cis Americans outside of medical-related fields, and major institutions such as mass media and the healthcare-industrial complex, still associate HIV/AIDS with queer communities as though it were somehow definitional. AIDS discourses have been influential and impactful in academic circles, queer communities, and some healthcare groups. Shifting, or encapsulating AIDS discourses into COVID discourses or chronic illness discourses maybe a more a more politically effective route to disassociate the concepts of “sexual identity” and “disease,” the false dichotomies of “normal” versus “abnormal,” or “disease” and “health” in broader mainstream culture.

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