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At the intersection of marginalised identities: Lesbian, gay, bisexual and transgender people's experiences of injecting drug use and hepatitis C seroconversion

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While the levels of injecting drug use among lesbian, gay, bisexual and transgender (LGBT) populations are high we know little about their experiences of injecting drugs or living with hepatitis C virus (HCV) infection. The loss of traditional family and cultural ties means connection to community is important to the wellbeing of LGBT populations. While some kinds of drug-use are normalised within many LGBT communities, injecting drug use continues to be stigmatised. This exploratory qualitative study of people with newly acquired HCV used semi-structured interviews to explore participants' understandings and awareness of HCV, seroconversion, testing, diagnosis and treatment. We present a secondary thematic analysis of eight LGBT participants of the experience of injecting drugs, living with HCV and having a marginalised sexual or gender identity.

Community was central to the participants' accounts. Drug-use facilitated connection to a chosen community by suppressing sexual or gender desires allows them to fit in to the mainstream; enacting LGBT community norms of behaviour; and connection through shared drug-use. Participants also described feeling afraid to come out about their drug-use to LGBT peers because of the associated stigma of HCV. They described a similar stigma associated with HIV within the PWID community. Thus the combination of being LGBT/living with HIV (a "gay" disease) and injecting drugs/living with HCV (a "junkie's" disease) left them in a kind of no man's land. Health professionals working in drug and HCV care services need to develop capacity in providing culturally appropriate health care for LGBT people who inject drugs.

Key words: Hepatitis C; HIV; Drug Use; Sexuality; Culturally-appropriate; health care

What is known about this topic:

- There are higher rates of injecting drug use among LGBT people than among heterosexual people.
- Despite normalised non-injecting drug use among some networks of LGBT people, injecting drug use remains stigmatised and invisible.

What this paper adds:

- Many participants described tensions around their place in two communities – PWID and LGBT – leading to a lack of support networks.
- The absence of support may place additional stressors on LGBT people considering HCV or drug treatment.
- Addressing drug use may also require individuals deal with issues related to sexual or gender identity.

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Australian and international research consistently documents high levels of injecting drug use among non-heterosexual populations (Hillier et al., 1998, Murnane et al., 2000, Fergusson et al., 2005, Hillier et al., 2005, McCabe et al., 2009, Conron et al., 2010, Hillier et al., 2010). Australian population-based data indicate up to 24% of non-heterosexual men and 14% of non-heterosexual women have injected drugs, compared to 3% of the general population (Grulich et al., 2003). These high rates of injecting drug use are reflected in younger LGBT Australians. Among 16-24 year olds (de Visser et al., 2006), non-heterosexual sexual identity was significantly correlated with lifetime injecting drug use (adjusted odd ratio (AOR) 14.04, 95% confidence interval (CI) 2.66-74.2 for males and AOR 7.81, 95% CI 1.42-42.90 for women). While a 2004 community study of same-sex attracted 14 – 21 years olds found 4% had ever injected drugs, prevalence was higher among young women (6%, versus 3% for young men; Hillier et al. (2005)). Australian research has also demonstrated that among regular ecstasy users, non-heterosexual participants had significantly higher rates of injecting than heterosexual participants (AOR 3.93; 95% CI 1.99-7.74 for women, AOR 1.89, 95% CI 1.04-3.40 for men; Degenhardt (2005)). There is no research on injecting among transgender people in Australia. A systematic review of risk behaviours among male to female transgender people in the US (Herbst et al., 2008) found a 12% prevalence of current injecting drug use among participants.

Yet little is known about the experiences of lesbian, gay, bisexual and transgender (LGBT) people who inject drugs (PWID). Limited social research on Australian LGBT people's experiences of injecting or living with HCV has repeatedly shown that while recreational drug use is normalised within LGBT communities and many report injecting drugs, injection remained highly stigmatised – something *“you should not even think about”* (Ellard, 2007, p230) and *“beyond the limit”* (Slavin, 2004, p437) of normalised recreational drug use in their community. In *Beyond Perceptions* (Murnane et al., 2000), a report on drug use among LGBT communities in Victoria, Australia, some participants reported how drug use was almost a *“rite of passage”* (p7) in the LGBT community.

Drugs were used to celebrate community and emphasize a sense of belonging. For other people, alcohol and other drug use posed a barrier to participating in community either by exclusion due to what was seen as inappropriate drug use or a lack of desire to socialize in the context of drug use. Although many participants in these studies reported injecting, they differentiated themselves from more entrenched PWID who they referred to as “*junkies*” (Slavin, 2004, p446). Despite the normalisation of non-injecting drug use as a means of enhancing sociability (Southgate and Hopwood, 2001) and/or sexual desire and longevity (Prestage et al., 2009) within some LGBT networks, it appears that PWID find difficulty identifying injecting networks even within visible urban LGBT communities.

Research on the lives of Australian lesbian, gay, bisexual and transgender (LGBT) people highlights the importance of community. This work has shown that LGBT people have less access to traditional support networks through strong family and cultural ties, such that connection to a LGBT community and/or friendship networks can be of more influence on general health (McNair et al., 2005, Couch et al., 2007, Hillier, 2007, Heath and Mulligan, 2008). These kinds of connections can ameliorate the negative effects of “minority stress” (Meyer, 2003), that is, where “stigma, prejudice, and discrimination create a hostile and stressful social environment that causes mental health problems”. In US research, a sense of belonging to a LGBT community was associated with lower levels of depression among self-identified lesbian women (McLaren, 2009) and gay men (Meyer and Northridge, 2007). In another study, high levels of social support were significantly related to lower levels of depression and higher levels of self-esteem (Zea et al., 1999). Data modelling from 183 same-sex and 275 mixed-sex relationships found better perceived social network support specifically for the romantic relationship predicted more positive mental and physical health outcomes for the partners, even when general social support and support for sexual orientation were controlled for (Blair et al., 2008). A recent Australian study found major depressive disorder was associated with less social support and less gay community involvement (Mao et al., 2009). One outcome of this research is an advocacy for community as a source of support (eg Barnard (2009)).

Community has been fundamental to the Australian public health response to HIV/AIDS (Zablotska et al., 2012, Altman, 1994, Dowsett, 1995, Dowsett, 1996, Kippax et al., 1993). Very early on, gay community drove the response to HIV/AIDS through political organisation and community-based education, while public health agencies leveraged community to develop and deliver interventions through existing community LGBT networks, events and media. This partnership approach is still part of the public health response to HIV/AIDS in the gay community in Australia.

Community has also been an important part of the Australian response to drug related harms. Carruthers claims the hepatitis C epidemic – and later HIV – provided the impetus and continues to drive the “consolidation of communities as a necessary part of the response to drug use-related harms” (2007, p1972). A PWID community provides a network through which behavioural interventions can be deployed, as well as a platform for applying political pressure on mainstream health services. In Australia, community is created and mobilised through organisations such as the NSW Users and AIDS Association (NUAA) which provides education, practical support, information and advocacy to users of illicit drugs, and the Australian Injecting and Illicit Drug Users League (AIVL), the national peak organisation representing state and territory drug user organisations. The early establishment of Needle and Syringe programs (NSPs) in Australia with the first (illegal) pilot in 1986

(Wodak et al., 1987) has been credited with containing the HIV epidemic (HIV rate among PWID in Australia is 1.5%). This early intervention was enabled through strong partnerships between sex worker and PWID activists and communities. Similarly, a community-based trial of naloxone prescription to PWID coupled with education and outreach to enable for administration by peers, family or friends in the case of opioid overdose commenced early in 2012 (Alcohol Tobacco and Other Drug Association ACT).

Given the high prevalence of injecting drug use among LGBT people, accounts of their lives are notably absent from the literature, both in LGBT literature covering drug use, and in PWID literature where gender and sexuality identities are discussed. The aim of this paper is to understand the experiences of Australians who are both PWID and LGBT and raise awareness of the health care needs of this marginalised group.

Methods

A large qualitative study of the experience of seroconversion to hepatitis C among people who inject drugs (PWID) in Australia sought to increase understanding of the practices, settings, networks and structures contributing to HCV infection. The project aimed to inform the nature and content of information provided to PWID, and/or policies and programs, including structural interventions, designed to prevent hepatitis C infection. During 2009, 24 participants with newly acquired HCV were recruited through advertisements placed in publications produced by two Sydney community organisations serving people living with HCV and/or PWID, and via referral from a longitudinal cohort study of HCV incidence among HCV-negative PWID. Screened by telephone, participants were eligible if they reported a positive HCV antibody test within the preceding two years, preceded by at least one negative test. Participants gave informed consent prior to participation and were reimbursed \$30. Ethical approval for the study was obtained from the University of New South Wales Human Research Ethics Committee. The lack of knowledge in this area, the complex and sensitive issues involved and the need for nuanced narrative data suggested a qualitative approach. Semi-structured interviews allowed us to achieve some consistency between interviews while also permitting interviewers to respond to the range of issues and perspectives that emerged in open-ended conversation. Questions explored participant's understandings and awareness of HCV, perceived seroconversion events, testing, experiences of diagnosis, attitudes to treatment and changes in risk practices. Interviews were audio-recorded and transcribed verbatim. Transcripts were checked for accuracy against audio recordings and de-identified by the removal (or replacement) of identifying information and assignment of pseudonyms. Findings of this study are reported elsewhere (Deacon et al., 2010, Treloar et al., 2010, Deacon et al., 2011).

Sydney is the most populous city in Australia and has a visible LGBT 'scene' based around the inner-city suburbs. The annual Sydney Gay and Lesbian Mardi Gras festival celebrating LGBT culture culminates in a street parade and after-party attracts hundreds of thousands visitors. Sydney also has an established drug and commercial sex scene which has centred around Kings Cross, which is adjacent to Darlinghurst, the suburb most closely associated with the LGBT community in the public imagination. Located in Kings Cross is the only medically supervised injecting centre (MSIC) in Australia, which has operated since May 2001.

In analysing data from the larger project, we noticed the larger than expected proportion of LGBT participants (33%) and a number of emergent issues specific to their narratives. As sexuality was not a focus of the study, participants were not systematically asked about their sexuality or gender identity, however, all were asked open-ended questions about intimate relationships. The eight participants described in this paper either self-identified as LGBT during the interview and/or disclosed they were in a same-sex relationship. Participants reflect the diversity of PWID found in the main study with three reporting heroin, three methamphetamine, one cocaine and one both heroin and methamphetamine as the main drug/s injected; all but one reported injecting drugs in the six months prior to interview and two disclosed co-infection with HIV (table 1). All participants resided in urban or inner-suburban Sydney and were aged between 21 and 42 years. Most (5/8) received income from a government benefit, two also reported income from sex work and five reported prior incarceration. The sample also reflected the diversity of LGBT identities: three women were in a relationship with another woman (but did not explicitly identify as LGBT); three men identified as gay; another participant identified as transgender (male to female) and was sexually attracted to men, while the eighth participant described ongoing gender identity issues with the irregular use of (prescribed, feminising) hormone therapy since 17 years of age and reported no recent sexual activity or particular sexual attraction. The socioeconomic profile of our participants was more akin to other PWID (Stafford and Burns, 2011) than other LGBT people (Richters et al., 2002, Lee et al., 2010).

Table 1: Demographic and drug use characteristics of participants

	N
Total	8
Median age (range), years	33 (21-42)
Sexual / gender identity	
Gay man	3
WSW	3
Trans	2
Main drug injected	
Heroin	3
Methamphetamine	3
Other/mixture	2
ATSI	2
Source of income*	
Government benefits	6
Employment	3
Sex work	2
Ever imprisoned	5

* Can be more than one

We used thematic analysis (Braun and Clarke, 2006) to conduct a secondary analysis of transcripts of the eight LGBTPWID. During close reading of the transcripts we paid particular attention to the role of sexuality in accounts of injecting, seroconversion and living with HCV, and to LGBT communities and social networks as contexts for injecting and living with HCV. We identified a number of themes including the place of injecting within same-sex relationships, experiences of loss of connection to LGBT community, and the use of drugs to cope with stigmatised LGBT identities. Across these issues, notions of connection, especially to community were pivotal, with participants talking repeatedly of fitting in with their chosen community and fears of rejection, of finding and keeping a place in a community where they felt they belonged. Thus, we will explore the experience of injecting drugs, living with HCV and having a marginalised sexual or gender identity through this lens of community connection.

Results

Community Connections

Our participants described three ways in which their drug use facilitated them fitting in – meeting the relevant norms - or connecting with their chosen communities (mainstream or LGBT community). First, drug use allowed some participants to suppress, mask or cope with sexual or gender desires that they experienced as undesirable or dangerous in homophobic or transphobic contexts. So, Matthew's heavy marijuana use helped him to suppress his desire to transition to female gender:

Well I first wore a dress when I was four years old and I've been dressing up in all my childhood years when I, when I got the chance. ... I was very drawn to ... wanting to do what girls do, you know. It really became a major issue in my teenage years. You know, to the point where mum actually kicked me out of home and said, "Right, that's it." ... there has been times where I've thought to myself, "Well there's no point in getting off pot" because whenever I get off pot all I want to do is have a gender change. (Matthew, aged 34)

Jess told a complex story of abuse and disadvantage with an early awareness of her transgender identity, HIV/HCV co-infection and how substance-use suppressed her emotional distress:

Oh yeah, [aware of transgender identity] even from like four, five, six, seven years old. Like you know ... I got expelled from primary school and that because I was just, I didn't know what, I thought it was wrong about how I was attracted to males and I wanted to be this way and not that way. And then I was being molested all the time so that was making it worse ... Yep, I started [injecting drugs] at 24 ... I caught HIV when I was 15 through having sex with these two adults that I trusted ... I found out when I was 15 ... Because from when I was, found out I was HIV positive, I was just a full-blown alcoholic. Right? As soon as I'd open my eyes I'd just like drink, drink, drink, drink ... like to block out knowing about having HIV ... Just I've tried to go like straight, straight [no drug use]. ... and like it still, it masks a bit of shield over my HIV like. And when, I noticed when I went straight like, have nothing in my system, I just like, I broke down like, you know. And nowadays like I'll get tears come to my, but I can't cry, I don't cry anymore, or ... like because I just get too scared; if I cry will I ever stop? (Jess, aged 38)

Second, drug use facilitated an important and desired connection with LGBT communities. Again this involved fitting in with a perceived way of being, what George described as “a successful homosexual”:

It's also, it's also part of ... I've never fitted into the gay community ... there are ways you have to behave and things you have to do to be a successful homosexual. When I go out to a gay bar on the rare occasions that I do, I spend several hours in the corner impersonating a potted plant. And, and that's part of the reason why when somebody offers me something relatively exotic, I'll go for it. (George, age 42)

Third, drug use allowed some of our participants to create intimate connections with others. In this account, George recounted a deliberate act of blood sharing in a sex scene with two other men that has clear resonances with barebacking (used here to mean intentional rather than unplanned unprotected anal sex; Ridge (2004)) for pleasure and intimacy (Holmes and Warner, 2005). While George recognised the risks of the practice after the fact – “that was nuts” “what the hell were you thinking” – in the moment, the meaning of sharing blood as connection was significant and primary – “it was special”; “I wanted to connect”.

*Three guys, including me, crystal meth, we all knew what each other had in terms of illnesses and we deliberately exchanged blood... As soon as I woke up ... I thought, “That was nuts. What the hell were you thinking?” But when I cast my mind back I do know what I was thinking. ... sex wasn't gonna happen and I wanted to connect with this guy in particular ... We'd stick a needle in each other's arm. We'd draw back on it. And we'd inject it into the next guy's arm ... Don't know why I'm grinning ... it was special at the time. ...It's, it's a **sexual** thing. If I'm, if ... if I and another guy are using needles I want to use his needle. It's a **sexual** thing. It's, it's **intimacy**, it's **connection** (George, 42)*

Community Disconnections

Injecting drugs and becoming infected with HCV could also be a barrier to fitting in or connecting with desired communities. For many participants both the expectation of rejection by a desired community and the experience of stigma associated with injecting drugs/ HCV was distressing. Being an injecting drug user disrupted the potential connection and valuable social support between Tegan and her new (gay) work colleague. While he felt able to come out to her about his sexuality and experience her acceptance, she did not feel free to come out about her injecting drug use for fear of his rejection. The developing friendship is already marked by secrecy and the fear of discovery and exposure.

I mean he's finally getting comfortable with me and actually he opened up and told me he's gay, and no-one at work really knew about it. And he knew I was with [her girlfriend] ... I can't say it [she injects drugs] to him because I feel like he's just gonna look at me, you know, like I'm just ... And it's like all these things I've gotta hide from him. Like I'm worried that he's, he knows and like he's gonna find out I'm at the methadone clinic one day and he might see me ... You know, I'm becoming really good friends with him and it's just, I still can't open up to him. (Teagan, 29)

A majority of our participants described a stigma surrounding injecting drug use in the LGBT community. HCV infection was also stigmatised insofar as it was a marker of injecting much like HIV acts as a marker of gay sex. Where HIV was “a gay disease” and could be part of gay identity and

community experience, HCV was a straight disease. This meant that a gay man with HCV was no longer recognisable as a “gay boy”; he was marked as a junkie (as not one of us).

But hep C is one of those things ... it's a junkie disease you see. And that's the way my community looks at it. HIV's been around for a long time ... and we, we rally for them ... hep C is a straight person's disease ... And you know, a gay boy getting hep C, you know, is a junkie. ... "You know, the only way you got it is being dirty. You must have been fucking dirty". (Wilson, 37)

Wilson's subsequent description of loss of identity and community – “my community” – and of having been rejected by his chosen community is poignant. His place in one community demands he monitor what he can think and say, his connection to the other is stifled unless he is intoxicated.

But I've kind of lost, lost touch with my community because of the stigma that's related to it. I think that might be one of the reasons why I find it so hard to get intimate with people because I'm surrounded ... by heterosexuals so ... I'm putting into myself the heterosexual persona. Okay, I've gotta think this way. I can't say this, I can't say that. ... and in the last I think eight months or so I've been doing that. ... I can't relate to gay people unless I'm really, really drunk. Whereas I used to be able to, of course. (Wilson, 37)

Our participants did not just describe losing their place in an LGBT community. Some described the stigma attached to being HIV positive among PWID. Again connection and acceptance was contingent on the suppression of particular aspects of self. Jess (HIV positive and HCV-exposed) contrasted the acceptance her injecting peers had of HCV infection – extending to a willingness to inject with her – with their fear of HIV.

But I think I think, you feel dirty with HIV because it's classified as an STD. And the names that they've got for it: the “bug” and stuff like that. ... And the stigma behind it because like, I don't know ... like you'll be in a group of people like, “I've got hep C, it's okay brother, it's okay.” And they'll use with you. “I've got HIV”. “Fuck that!” (Jess, aged 38)

Discussion

Connecting with a community of like-minded others produces a sense of belonging, solidarity, and acceptance. It creates a space where we do not have to explain, hide, or justify ourselves. This is not what the eight participants in our study described. While specific practices, identity and infectious diseases that are highly stigmatised in the broader community were to an extent accepted within each community, the combination of LGBT/living with HIV (a “gay” disease) and injecting drugs/living with HCV (a “junkie's” disease) put our participants in a kind of no man's land. There was a strong sense of not belonging in either place, although some were able to pass sufficiently to be accepted as long as they were careful about who they told and what they told them.

Recent publications suggest that the role of community in Australian gay men's lives is changing, and reveal an ambivalence among writers about the existence of a “gay community” (Holt, 2011, Reynolds, 2002, Reynolds, 2007, Robinson, 2009, Rosser et al., 2008, Rowe and Dowsett, 2008, Zablotska et al., 2012). Rowe and Dowsett (2008) found ambivalence towards the gay community in the late 1990's, and that what may be described as one community was really fragmented into “urban tribes”. Another writer adopted the alternative phrase “personal communities” to describe the nature of the communities and networks (Holt, 2011). Holt found men in the study gained a sense of belonging from broad networks of friends where sexuality was not the only organising factor, and this was more marked for younger people. However, men still valued close, supportive

relationships with gay men and attended community events. While not all LGBT people feel LGBT community connection is important for them, for the people in this study it was universally important.

What we see in these accounts are the consequences of the failure to be recognised by others as part of a chosen community, and of having identity denied or threatened. The participants in our study clearly want but are unable to find a secure connection with community. Instead, acceptance was contingent on suppressing a part of themselves – if you inject drugs or are HCV positive then you cannot be LGBT, if you are HIV positive then you cannot inject with us. Wilson denied his identity as a gay man, and Tegan could not be herself with someone for whom she presumed a sense of solidarity. This cannot but have psychological consequences for a sense of self and of self-worth.

Being a LGBT PWID is a qualitatively different experience to being a heterosexual PWID. Their experience of injecting drug use is often in the context of marginalized gender and sexuality identities. They had already experienced mainstream community rejection and then experienced rejection from the very community they have sought acceptance (LGBT, and for some PWID). We know that the experience of being LGBT is associated with increased risk of mental health problems, problematic alcohol and drug use and that many people also experience discrimination (or expect to) in seeking health services. For LGBT people considering HCV or drug treatment, the absence of a supportive network may place additional stressors with previous research showing improved success for people with greater social support (Hopwood et al., 2006, Laudet, 2008, Sgorbini et al., 2009, Dore et al., 2010). The absence of discussion of sexuality in PWID literature, despite the high prevalence of LGBT PWID, raises questions about the provision of culturally safe health care.

There is compelling evidence that LGBT people seeking health care in general face a lack of awareness and knowledge of their health needs, and many directly experience homophobia and discrimination (McNair, 2000, Saulnier, 2002, Hinchliff et al., 2005). We know little about what this means for the large proportion of PWID who are LGBT and seeking HCV- or drug-related health care. A study of Australian lesbian and bisexual women's experiences of living with HCV found their needs were less satisfied, they felt more hostility from medical professionals, and were referred less often to specialists compared to heterosexual women (Banwell et al., 2005). Yet the provision of sensitive and inclusive health care relies on awareness of the needs and challenges facing this population (Mayer et al., 2008, Ministerial Advisory Committee on Gay Lesbian Bisexual Transgender and Intersex Health and Wellbeing, 2009).

Recommendations

It is clear from our findings that addressing drug use in LGBT individuals living with HCV may also need to deal with issues around sexual or gender identity. Health professionals in this area may need to develop relationships with LGBT community health organisations and pursue opportunities to develop capacity in LGBT health care (Mayer et al., 2008, Ministerial Advisory Committee on Gay Lesbian Bisexual Transgender and Intersex Health and Wellbeing, 2009).

While LGBT community organisations have traditionally focused on HIV, a move towards holistic community health provision will allow a more effective focus on injecting drug risk and HCV infection. In Australia, we have already seen this shift with ACON, Australia's largest community-based LGBT health and HIV/AIDS organisation, now running a Substance Support Service incorporating a phonenumber and counselling service. This was part of a larger program that included a study of LGB methamphetamine users (Matheson et al., 2010). Lessons from the HIV epidemic can

be applied here; emphasising “partnerships, a community focus, the right of people living with HIV/AIDS to self-determination and a sense of shared responsibility” (ACON, 2010). Community organisations could also raise awareness of HCV in LGBT communities and HIV in PWID communities to reduce stigma for people whose experiences exist at the intersection of these marginalised identities.

Finally, the first step to raising awareness of LGBT PWID is to start collecting data. Questions on markers of sexuality – behaviour, identity and community attachment – need to be considered a routine part of the provision of health care and the conduct of research.

Conclusions

Our findings should be understood in relation to the context in which data was collected. Our interview schedule did not include questions on sexuality so people in the larger sample who did not disclose an LGBT identity or a same-sex relationship were not part of our analysis. Our findings may reflect the concerns of people for whom a LGBT identity was especially salient, or who felt safe to disclose it to our interviewers. We also did not ask specific questions about injecting or HCV in relation to sexuality; such questions may have elicited different accounts. Our analysis is based on a small and diverse sample of eight LGBT injectors living with HCV in Sydney, Australia. We make no claims that our findings reflect the depth and breadth of experience among LGBT people. Our intention is to start a conversation with health professionals working in drug and HCV care services, about the needs of their LGBT clients.

Our findings reveal particular issues relating to LGBT identities which compound the stigma associated with injecting drug use and HCV infection. Two themes were identified: drug use and connection, and HCV and loss of connection. We found that drug use was intricately tied up in participants’ identities and both enhanced and negatively impacted their ability to connect with other people and communities. Being infected with HCV often shattered connections and compounded felt stigma. The compelling experiences related by these LGBT people provide insights into issues pertinent to health care professionals, researchers and educators.

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