Personal, interpersonal and structural challenges to accessing HIV testing, treatment and care services among female sex workers, men who have sex with men and transgenders in Karnataka state, South India

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ABSTRACT

Background Despite high HIV prevalence rates among most-at-risk groups, utilisation of HIV testing, treatment and care services was relatively low in Karnataka prior to 2008. The authors aimed to understand the barriers to and identify potential solutions for improving HIV service utilisation.

Methods Focus group discussions were carried out among homogeneous groups of female sex workers, men who have sex with men and transgenders, and programme peer educators in six districts across Karnataka in March and April 2008.

Results 26 focus group discussions were conducted, involving 302 participants. Participants had good knowledge about HIV and HIV voluntary counselling and testing (VCT) services, but awareness of other HIV services was low. The fear of the psychological impact of a positive HIV test result and the perceived repercussions of being seen accessing HIV services were key personal and interpersonal barriers to HIV service utilisation. Previous experiences of discrimination at government healthcare services, coupled with discriminatory attitudes and behaviours by VCT staff, were key structural barriers to VCT service uptake among those who had not been HIV tested. Among those who had used government-managed prevention of parent to child transmission and antiretroviral treatment services, poor physical facilities, long waiting times, lack of available treatment, the need to give bribes to receive care and discriminatory attitudes of healthcare staff presented additional structural barriers.

Conclusions Embedding some HIV care services within existing programmes for vulnerable populations, as well as improving service quality at government facilities, are key to overcoming the multiple barriers to service utilisation. Increasing the uptake of HIV testing, treatment and care services is key to improving the quality and longevity of the lives of HIV-infected individuals.

INTRODUCTION

Early diagnosis and treatment of HIV-infected individuals is essential in promoting the long-term health and survival of people infected with HIV and can help prevent onward HIV transmission to sexual partners and infants of infected mothers.1 Despite the recent expansion of free antiretroviral treatment (ART) across the developing world, many HIV-positive individuals remain unaware of their status and do not benefit from ART.2 This is particularly true for some vulnerable populations, such as female sex workers (FSWs), and men who have sex with men and transgenders (MSM-T), where the limited numbers of studies available suggest that fewer than 20% have accessed voluntary counselling and testing (VCT) services.3 4 The few qualitative studies conducted with FSWs and MSM-T suggest that a lack of knowledge about HIV/AIDS, VCT and ART, lack of perceived risk, anxieties about a positive test result, fears about being seen accessing HIV services, discrimination by healthcare providers and the fear of arrest may act as major disincentives to HIV testing.5–8 The ‘double stigma’ of an HIV-positive result, coupled with the potential disclosure of sex work and/or a stigmatised sexual orientation, can present additional barriers.5–8

India has an estimated 2.4 million people living with HIV.9 The HIV epidemic is highly heterogeneous, with the majority of infections occurring through heterosexual transmission. Unprotected paid sex is a major transmission route, particularly in the southern Indian states. Karnataka state in south India has an estimated adult HIV prevalence of >1% in several districts and has the fourth highest HIV prevalence among the general population among Indian states. Karnataka has over 100,000 FSWs and 25,000 MSM-T, of whom approximately 17% are estimated to be infected with HIV.10–12

Sex work and same sex relationships are highly stigmatised within Indian society, and FSWs and men who have sex with men (MSM) frequently experience discrimination from their families, neighbours and even the state.5 8 13 14 MSM and hijras (transgenders) may or may not sell sex and may have sexual encounters either as a livelihood option or as an opportunity to assert or explore their sexuality.5 The Karnataka Health Promotion Trust (KHPT), supported by the India AIDS Initiative (Avahan) of the Bill and Melinda Gates Foundation, was established in December 2005 with the aim of developing and rapidly scaling up targeted interventions on HIV prevention among high-risk populations (FSWs, MSM and transgenders) in 18 of 27 districts in Karnataka.15 16 As part of this process, dedicated sexually transmitted infection (STI) services for FSWs and MSM-T were established in every district, with these key populations (KPs) consulted on clinic locations and...
opening times and included in the recruitment and training of counsellors and medical staff. To reduce (conscious or unconscious) stigma and discrimination by clinical staff towards women who sell sex and MSM-T, it is important that they understand and accept the sexuality and the work of the FSW and MSM-T communities. To facilitate this, staff employed by such STI services receive classroom as well as experiential training through dialogues and exposure to KPs. In addition, STI clinic committees, headed by FSWs and MSM-T, were established in each district, providing a forum where any grievances towards clinical services could be aired and re-dressed. Due to the non-availability of affordable HIV care and support services when the HIV prevention programmes were originally implemented (2003–2004), HIV testing was not actively promoted initially.

However, since 2006, there has been an exponential increase in government-funded HIV care and support services throughout India in response to the escalating HIV epidemic, with the number of ART centres offering free HIV treatment increasing from 40 to 292 between 2006 and 2010. In response, the HIV prevention programmes began promoting improved access to VCT and HIV care services as part of efforts to improve health and well-being among FSWs and MSM-T. However, despite high HIV prevalence rates among FSWs (16.5%) and MSM-T (17.6%), utilisation of free government HIV services by these populations in Karnataka was initially low, with only 28% of FSWs reporting ever having been tested for HIV in 2005–2007. This qualitative study was conducted as a needs assessment within the context of the Avahan programme to understand the barriers to accessing HIV care services across different typologies of FSWs and MSM-T and to identify strategies to overcome them.

MATERIALS AND METHODS

Study population and recruitment

Focus group discussions (FGDs) were conducted with homogeneous groups of 6–15 FSWs, MSM-T and peer educators in six districts across Karnataka in March and April 2008. The districts were selected purposively to represent different geographic regions across the state (north, Belgaum; south, Bangalore; east, Bellary; west, Davangere; central, Hubli and Dharwad). Participants were recruited purposively, with the help of the local implementing non-governmental organisations (NGOs), and witnessed verbal informed consent was obtained from each participant before each focus group. FSWs, MSM and peer educators were interviewed in each district, with 8–15 participants recruited for each focus group. The number of FGDs conducted with FSWs, MSM and peer educators was decided based on the proportion of the total population of these groups in each district. FSWs were selected based on the predominant typology of FSW present in that district (street-, brothel- or home-based). Where two or more typologies were present in equal numbers, FGDs were conducted with each typology. In addition, in districts where women sold sex in both rural and urban areas, FGDs were conducted with both rural and urban FSWs. Transgenders were interviewed in Bangalore only, where there are relatively high numbers from this community.

FGDs and analysis

Each FGD was led by a trained facilitator in the local language, Kannada, who followed guidelines developed for this study. Facilitator’s had postgraduate qualifications in social sciences, were fluent in the local language and had a minimum of 3 years experience in collecting qualitative data for similar projects. Prior to the study, they received training by KHPT in FGD facilitation and data recording and were supported by senior staff during the period of data collection.

Focus groups discussed knowledge around HIV transmission routes; perception of own/community to risk of HIV; benefits and drawbacks to knowing one’s own HIV status; and experiences, barriers and suggestions to utilizing VCT, prevention of parent to child transmission (PPTCT), HIV care and support, and ART services. Interviews were tape-recorded, transcribed, translated into English and analysed for persistent themes and ideas.

RESULTS

Study population

Three hundred and two individuals participated in 26 FGDs. Their group categories, mean age and age range, typology, district and number per group are shown in table 1. Eleven FGDs were held with 125 FSWs; five FGDs with 56 MSM (kothis and double-deckers) and one FGD with six transgenders (hijras). Kothis are effeminate men who may cross-dress but remain biologically male; double-deckers are primarily sexually oriented towards men, but their gender identity is more masculine or neutral than kothi. Hijras are male-to-female transgenders who may or may not be castrated. In addition, seven FGDs were held with 87 female peer educators and two focus groups with 28 male peer educators (table 1). The mean age of participants was 30.5 years (range 18–59 years), and all KPs were registered with the local implementing NGO HIV prevention partner.

Personal factors influencing HIV service utilisation

Most participants had comprehensive knowledge about HIV and had accurate perceptions of their vulnerability to HIV infection. Several examples were cited of situations where a condom may not be worn and community members may be exposed to infection: unprotected sex for increased payment, trusting a regular partner or spouse, rape, client secretly tearing or removing a condom during sex, condom breakage during anal sex, alcohol use reducing impetus to use a condom and unprotected sex for increased sexual pleasure.

The fear of the impact of a positive HIV result on an individual’s mental health presented a major barrier to FSWs and MSM-T accessing VCT services (table 2), with respondents underlining how serious this issue was with several examples of individuals contemplating or committing suicide after learning about their positive status. As a result of this fear, some reported going for testing, but not returning for their results, while others were in denial that they could be HIV positive, as they did not have any symptoms to suggest that they were unwell. Several explained that community members would prefer to remain ignorant of their HIV status rather than face the knowledge that they were HIV positive.

Many people resort to their fate and decide to live as long as their fate permits them and one day die quietly. Everyone has to die one day, no one can escape. This is the kind of philosophy they follow. (Female peer educator, Hubli)

In addition, although most groups knew about VCT services and where they could access them, some participants mistakenly thought that the STI tests carried out at the NGO clinic included HIV testing. Furthermore, few participants (mainly peer educators) had information or experience of

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In the event of a negative test result, participants described the relief of knowing one’s negative status and their strengthened resolve to resist unprotected intercourse in the future.

**Interpersonal factors influencing HIV service utilisation**

The main interpersonal barrier to FSWs and MSM-T accessing HIV testing and treatment services was the pervading fear of discrimination from families, neighbours, landlords, schools and others following inadvertent disclosure of sex work, homosexuality and/or an HIV-positive status. Many participants had either witnessed or experienced sex work, MSM-T or HIV-related discrimination, including being physically abused or abandoned by husbands and families; being made destitute, being ‘taunted’ or ‘looked down upon’ by neighbours; people living with HIV/ART, antiretroviral treatment; FSW, female sex worker; MSM-T, men who have sex with men and transgenders; NGO, non-governmental organisation; PPTCT, prevention of parent to child transmission; STI, sexually transmitted infection; VCT, voluntary counselling and testing.

Table 2. Summary of the key personal, interpersonal and structural factors influencing HIV service uptake by FSWs, MSM and transgenders in Karnataka state

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Motivators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal</td>
<td>Lack of knowledge about HIV services; denial of HIV risk/fatalism; fear of mental health impact of a positive test result</td>
</tr>
<tr>
<td>Interpersonal</td>
<td>Fear of discrimination by family, neighbours, schools and government officials following inadvertent disclosure of sex work, homosexuality and/or HIV infection</td>
</tr>
<tr>
<td>Structural</td>
<td>Discrimination and homophobia; derogatory comments; denial of treatment; diagnosing without examination; ineffective treatment; poor facilities at PPTCT service points</td>
</tr>
<tr>
<td>Quality of care</td>
<td>Location within hospitals; queuing for HIV services in hospital corridors; counselling facilities at VCT centres</td>
</tr>
<tr>
<td>Confidentiality</td>
<td>Long distances; charges for ‘free’ services; long waiting times; quotas at ART centres; ID cards and ration cards; a ‘buddy’ to access ART services</td>
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ART, antiretroviral treatment; FSW, female sex worker; MSM-T, men who have sex with men and transgenders; NGO, non-governmental organisation; PPTCT, prevention of parent to child transmission; STI, sexually transmitted infection; VCT, voluntary counselling and testing.
AIDS (PLWHAs) being locked in cages or sheds in villages until they died; nobody conducting the last rites following the death of an HIV-positive person; landlords refusing to rent their houses; and children of positive sex workers being disallowed admission by schools:

There was this woman who had visited Bombay for a while. She had HIV... Doctor advised her family to take good care of her. But, her family did not take care of her well. After they learned she had HIV, they kept her away in a farm house in their field. Then they shifted her to a shed where waste was dumped. They were not feeding her properly. She ultimately died there. (Brothel-based FSW, Belgaum)

MSM-T were also fearful that if they underwent HIV testing and were found to be HIV positive, they would experience discrimination from within the MSM-T community:

If someone is HIV positive, even our own people move away from them. Our own community members do like that. That is why for the fear of disclosure none of us dare to get tested. (Hijras, Bangalore)

For rural women, as babies are traditionally delivered by village elders at home, choosing to give birth in a hospital setting (in order to receive nevirapine) would invoke intense scrutiny and risked arousing suspicion, both of their sex work and their HIV-positive status:

Those people living with HIV, for the fear of husband and in-laws coming to know about their status, prefer to have the delivery conducted at home. (Female peer educator, Davangere)

Structural factors influencing HIV service utilisation

Perceived quality of care

Discriminatory attitudes of staff working at government healthcare facilities, especially towards those who are sex workers, from sexual minorities and/or who are HIV positive, were the major demotivators to FSWs and MSM-T accessing HIV services. Discrimination and homophobia were elaborated in terms of derogatory comments made by service providers; little understanding among service providers about sex work and sexuality; assumptions by service providers that participants were HIV positive because they sell sex; refusal by service providers to treat patients, including sending patients to the back of the queue or to different hospitals, prescribing medication without conducting a medical examination and prescribing ineffective treatment:

On our visit to a VCT, they treat us like garbage. They ask us to queue up, stand here, stand there... We feel bad about this. We thoroughly regret going there. We prefer to die than to get insulted like this. They treat women in sex work with insult and discrimination. (Female peer educator, Hubli)

Among those FSWs and MSM-T who had not accessed VCT services, experiences of discrimination at other government healthcare facilities were a key structural barrier to accessing HIV services. However, although actual discrimination against FSWs was reported at ART centres and some PPTCT services, this was not true for most VCT or care and support centres, where there were several reports of kind sensitive counsellors and medical staff. Thus, the fear of discrimination by FSWs was not always realised in practice, especially at VCT services. However, among MSM-T who had accessed HIV VCT, ART and other treatment and care services, homophobia and discrimination were again reported:

I have a fear that people may taunt me for having a ‘womanly’ feeling. When I went to a government hospital, they discriminated against me. They looked down on me. Made me stand and wait here and there. Made me stand in the queue till all others are attended to. With all this suffering, when I ultimately went inside, there also they taunted me, looked down on me. I felt very bad. I terribly regretted for having gone there. (Male peer educator, Hubli)

Although questions on NGO-run STI services were not included in the FGD guidelines, a clear unexpected outcome that emerged was community members’ high regard for the NGO services. In particular, participants reported trusting the staff and the services provided by the NGO STI clinics and valued the ‘exclusivity’ provided by these services. They felt comfortable to disclose that they were sex workers and were confident that consultations between the doctors at the NGO clinics and themselves would remain confidential:

If we undergo testing in our organization, the matter remains confidential and it is done free. It is not the same in government hospital, so we undergo test here only. (MSM, Davangere)

When staff were sensitised towards FSWs and MSM-T, either because they worked as clinical staff at the NGO STI clinic or because they had visited the project centres to learn about these communities, participants reported feeling comfortable to discuss their sexuality and their medical problems and motivated to access HIV and STI services:

Though the services in government hospital are also almost free, we are not able to openly speak about our problems. But here we are comfortable in talking to our doctor. They patiently listen to us (Home-based FSW, Bangalore)

We don’t consult outside. Because, I don’t know how to express the fact that I am MSM. That is why I don’t go. Whereas in our clinic, there are people known to us, we can freely share our problems with them... (MSM, Hubli)

Confidentiality

Another structural barrier to FSWs and MSM-T accessing HIV services involved concerns around maintaining confidentiality, both when accessing HIV services located within hospital settings (where they may be seen by a family member or neighbour) and during VCT sessions held in chambers, which could be overheard by people in the waiting room. Maintaining confidentiality was particularly problematic at ART centres, where patients had to queue for several hours underneath signs for ‘HIV-positive people’:

Only ____ knows that I am positive. I would have disclosed my positive status only to him. It is not public. But when I go there and wait in the queue, that I am HIV positive is made public. Everyone knows it. All of them standing in the queue in the ART Centre are positive only. It is certain that they have come to receive ART treatment. It has become very difficult to receive ART treatment. (MSM, Bangalore)

Barriers to service utilisation

Key barriers to utilisation of HIV services reported by FSWs and MSM-T, included having to travel long distances to access services, costs associated with travel and with bribes for ‘free’ services, loss of earnings when not selling sex and the requirements for ration and ID (identity) cards (which are often not available to these populations) to receive treatment. In addition, ART services were reported to be overstretched and under-resourced, with monthly ART quotas and ART drug rationing by staff, shortages of CD4 testing facilities and long waiting
times lasting several days. ART services also required patients to present ID and ration cards and to take a ‘buddy’ or family member (to help with adherence) before they would issue treatment, effectively prohibiting many community members from accessing treatment:

One of the patients had come from another district. They were very serious. When they went there [the ART centre] the first day, they were sent back as the time of consultation was up. They said they attend only for one and a half hours and asked them come during that time. The patient is not able even stand, impossible to hold him also. He was crying like anything. Counselling was done. It did not go well. Counsellor’s style was unsuitable for him, he was crying. Finally, they said that ART has to be given. Then they asked for the ration card. This person said, I don’t have a ration card and I am from Bellary. The moment they came to know that the person is from Bellary, they said, there is an ART centre in Bellary itself. Districts have quotas. Here treatment quota is available only to those who belong to Dharwad district, Bellary people don’t have a quota here. You go to Bellary hospital, they give ART treatment there only. (Male peer educator, Hubli)

Among some brothel-based FSWs who felt unsafe leaving the confines of their brothel, the threat of physical or sexual abuse by ‘rowdies’ or gangs presented additional barriers to service utilisation.

NGO peer educators were reported to use various strategies to overcome barriers to service utilisation, including providing emotional and practical support by accompanying community members to HIV services and paying their transport costs. Some NGOs had successfully advocated with government HIV treatment and care services, resulting in positive changes to staff attitudes and the removal of charges for ‘free’ services:

Last time I have warned them. I told them if you treat us like this again I am going to write to Bangalore. After such encounter, now whenever they see me, they ask me to come up and ask who I have brought with me. They respect me now. (Female peer educator, Hubli)

**DISCUSSION**

The recent scale-up of HIV testing, treatment and care services across many regions of the developing world aims to increase the longevity and quality of the lives of PLWHAs and also forms a key strategy for HIV prevention. However, despite great HIV treatment and care needs, FSWs, MSM and transgender communities undermine these services for a variety of reasons, including the fear associated with a positive test result and fears of HIV-related discrimination and recrimination by family, neighbours, healthcare providers and the state. The results of our study in Karnataka suggest that multiple personal, interpersonal (community) and structural (service provider) factors influence HIV service utilisation by this population and will need to be addressed if uptake of HIV testing, care and support services is to improve.

Unlike elsewhere, FSWs and MSM-T in our study had comprehensive knowledge of HIV transmission routes and accurate perceptions of their communities’ elevated risk of infection. In addition, many knew about VCT services. A lack of knowledge about ART, care and support and PPTCT services, coupled with the fear of a positive test result, were the major personal barriers to HIV service use. Educating peer educators more fully about HIV services is required, so that this information can be communicated to their peers. In addition, as indicated by some participants in our study, developing a clear understanding of the benefits of early HIV diagnosis may help individuals overcome the fear of being tested for HIV.

The main interpersonal barrier to HIV service utilisation by FSWs and MSM-T was the fear of reprisals by family, neighbours and the wider community. Given the significant societal discrimination against sex work, sexual minorities and PLWHAs, the unwillingness of FSWs, MSM and transgenders to access services and undergo HIV testing is not surprising. Similar to elsewhere, for participants in our study, accessing these services in hospital settings risked the double stigma of being exposed as a sex worker/MSM-T and as someone infected with HIV. Developing dedicated HIV testing services for FSWs, MSM and transgender populations within existing NGO-operated STI services, which are located away from hospital settings in sites selected by the community, could help overcome fears of being seen accessing these services. Furthermore, the entrenched societal prejudices held against these communities need to be addressed, for example, through education, awareness and sensitisation campaigns aimed at the whole community, and by changes in attitudes that discriminate against individuals based on their occupation, sexual orientation or HIV status. To this end, the KHPT has been working in collaboration with state and local government and police forces to advocate for policy changes to prohibit sex worker-associated violence and discrimination, and with journalists to address societal stigma by changing the ways in which the media report on these issues.

Experiences of FSW, MSM-T and HIV-related discrimination at government-run healthcare services were common and served as a powerful structural barrier to accessing government-run HIV services. Similar experiences have been described across Asia. Clearly, staff training programmes to develop better understanding and acceptance towards stigmatised communities such as MSM-T and FSWs and policies prohibiting the discrimination of patients based on their occupation or sexuality are needed. Indeed, when clinical staff had been exposed to these communities through training programmes designed and facilitated by FSWs and MSM-T, either because they worked in the NGO STI clinics or because they had visited the NGO projects to learn more about the community, kind, respectful and non-judgemental attitudes were reported by study participants, who said that they felt comfortable talking to such staff about their problems.

Several structural barriers to service access also contributed to low HIV service uptake, and these can be dealt with in different ways. Some NGO peer educators help community members overcome cost, distance and waiting time barriers by accompanying them to the various HIV services and will need to be addressed if uptake of HIV testing, care and support services is to improve.

Government ART services were reported by FSWs and MSM-T to be overstretched and under-resourced, with the demand for these free services evidently high. Ensuring that government ART services have the resources to cope with demand is vital to reduce the morbidity and mortality of PLWHAs. Furthermore, current HIV service policies that require ID cards, ration cards and a ‘buddy’ effectively prohibit many KP members from accessing ART and other HIV services and need to be addressed. Although the ‘buddy’ system was introduced by ART services to help with adherence, it has not worked well among the FSW and MSM-T communities as these populations...
What is already known on this subject

► There is a paucity of data examining the barriers to uptake of VCT and of HIV care and treatment services by FSWs and MSM-T in developing countries.
► Stigma is known to be a significant barrier, but it is unclear how this affects access to HIV services by FSWs and MSM-T.
► This study was conducted to understand the factors contributing to the low uptake of government-run HIV testing, treatment and care services by this population in Karnataka state, South India.

What this study adds

► Personal, interpersonal and structural barriers were identified, which prevent many sex workers from accessing government-managed HIV services.
► These barriers did not exist for NGO-run STI services dedicated to sex workers.
► We suggest embedding HIV testing services within dedicated clinics for FSWs and MSM-T and improving service quality at government HIV treatment and care facilities to help overcome the multiple barriers to service utilisation.

are already highly marginalised and are reluctant to disclose their HIV-positive status to anyone for fear of additional stigma and loss of business. Strategies to destigmatise HIV-positive sex workers are needed if a ‘buddy’ system is to help rather than hinder access to ART among these communities. In addition, training HIV-positive peer educators to act as role models to motivate their community members to access HIV services may help to destigmatise HIV infection among the FSW and MSM-T communities.

This study had several limitations. The purposive selection of districts, to include different geographic regions across the state, and the purposive selection of study participants by the NGOs, means that the study population may not be representative of the FSW/MSM-T population as a whole. However, the consistency of reporting of the key themes emerging from the study across focus groups and districts suggests that this is unlikely. In addition, transmitters were selected from Bangalore only, and as such their views were likely under-represented. Finally, with a sensitive topic such as HIV, reporting bias may have resulted in the under-reporting of unfavourable experiences at HIV services, particularly because participants were interviewed in groups instead of individually.

In conclusion, multiple personal, interpersonal and structural barriers prevent utilisation of HIV services by FSWs and MSM-T. Overcoming these barriers will require a multifaceted approach, involving FSWs, MSM-T, local communities, service providers and policy-makers. Continued education of these vulnerable populations and their families and communities on HIV transmission and prevention and HIV testing and treatment services, as well as on the benefits of early HIV diagnosis, is necessary to overcome personal barriers to accessing services. Dedicated sex worker HIV testing services provided as part of the standard package of care by NGO-led STI clinics could help to overcome the interpersonal and structural barriers to accessing testing services. Facilitating access to HIV testing and treatment services is crucial in enabling PLWHA to claim their right to good health and also to enhance HIV prevention.

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Contributors TS HB designed the study, performed the analyses and wrote the first draft of the paper. PB designed the study and contributed to writing the paper. MS designed and oversaw local implementation of the study. BMR and SI designed and supervised the study. SM designed the study and contributed to writing the paper.

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Competing interests None.

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