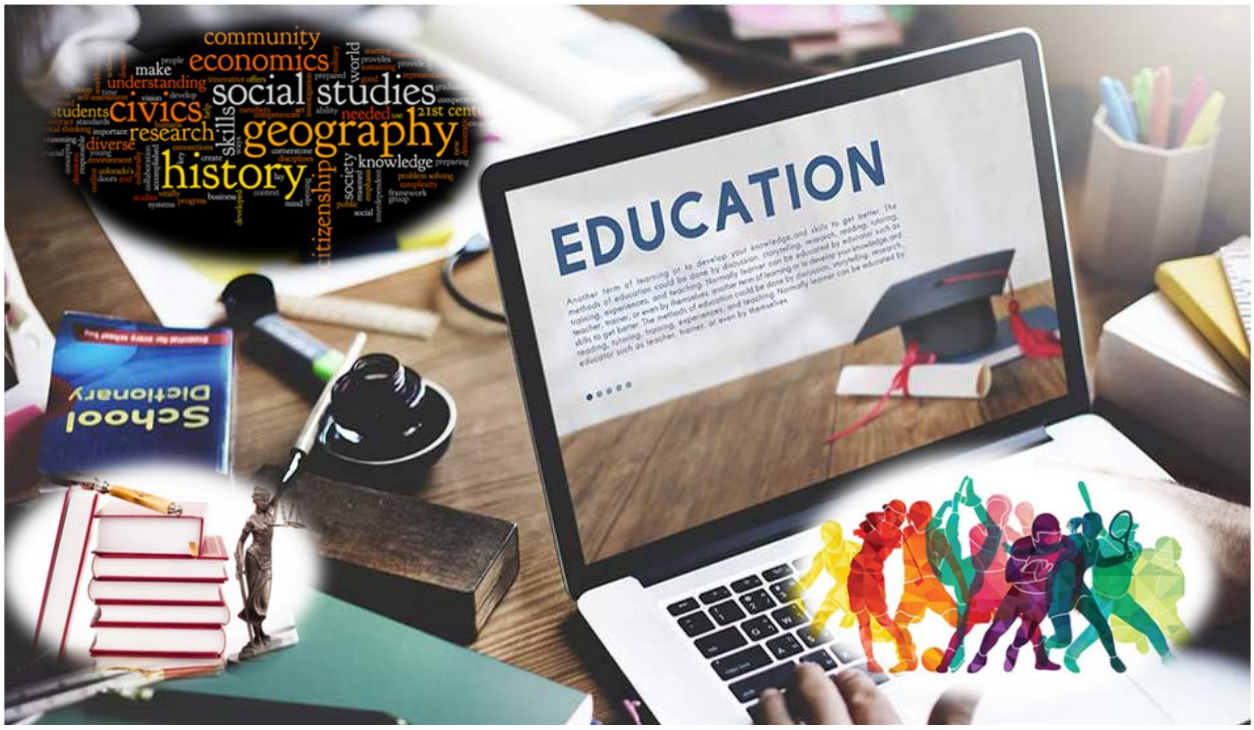

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Research Article

SOCIAL CONSTRUCTION OF HIV/AIDS: UNDERSTANDING THE DILEMMAS AMONG THE FAMILY

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ABSTRACT
Since the inception of HIV/AIDS, myths and misconception has ruled the mind of individuals which has eventually leaded to social construction of HIV/AIDS among the family members. Various issues came in front as a consequence of misinterpretation of this illness. Family, one of the most essential features of human socialization remains the most impacted and affected. It depicts the culturally constructed meaning which leads to social fabrication of HIV among the families. It girdles sex and sexuality and attributes the promiscuous sexual behaviour towards an individual living with HIV/AIDS. It is characterizes the past experiences, norms, values, behavioural patterns and beliefs of individuals from different social background. The present paper is an aim to understand the way HIV/AIDS is socially constructed among families, community and society. It will also depict the various ways in which HIV infection and AIDS as a disease is anticipated and deciphered by individuals

Introduction

The basic contentions of the argument are implicit in its title, that reality is socially constructed and an attempt is complete to be acquainted with the process in which social construction makes its existence. As Berger and Luckmann (1966) put that the 'Reality' and 'Knowledge' is a relative term. Anything may be real for a section of society but not for everybody. The meaning of what is real and the process of reality construction varies from society to society. For instance, AIDS carries different cultural meanings outside of Western Europe and North America. In Africa, where male-female intercourse is the primary transmission route, the social construction of AIDS is marked by the hierarchy of gender and the stigma of poverty and the 'gayness' of the syndrome is much less salient. In Kenya, HIV infection rates are highest among the working class population living in urban areas, but cultural proscriptions against discussing sex make it difficult to educate people about how to protect themselves (Rollins, 2001).

People belonging to the different sects of society might perceive same object in variant ways. They tend to add their perception and ideology in representing the problem and thus create their version of reality. Though a person's conception of reality, fear and danger, abnormality and stigma, health and beauty may be very individual, but this perception, to a large extent, is culturally patterned. Events, actions, attitudes, and beliefs are mediated by historical and cultural factors. Individual reality is a social construction and not necessarily an absolute truth. Personal conceptions are reflective of a much larger construct, one that transcends any individual. The relationship,

however, between individual perception and social construct is an integral one in which the dynamic socialization shapes the construction of reality (Huber, 1998).

Man is biologically predestined to construct and to inhabit a world with others. This world becomes for him the dominant and definite reality. Its limits are set by nature, but once constructed, this world acts back upon nature. In the dialectic between nature and the socially constructed world the human organism itself is transformed. In this same dialectic man produces reality and thereby produces himself (Berger and Luckmann, 1966).

HIV/AIDS has altered the model of information production and consumption and has spawned its own vernacular, one representative of a diverse population of information producers and consumers. Further compounding this complicated communications picture, the body of information surrounding HIV/AIDS continues to grow at an epidemic rate, often in tandem with the numbers of reported cases. Various domains shape the construction of HIV/AIDS as chronic disease, including the political, social, economic, legal, philosophical, psychological, religious and spiritual ramifications associated with the illness (Huber, 1998).

A body of knowledge concerning HIV/AIDS exists in the societal construction which mirrors the complexities of the malady and the various controversies associated with it. This body of knowledge of a disease is a body of knowledge that breathes life into the pathological by providing it visibility that exists because of HIV/AIDS. Disease and the respective body of knowledge co-exist within a social reality, a social reality that binds and circumscribes. Consequently, the organizational schema of a controlled vocabulary designed to facilitate knowledge organization relative to HIV/AIDS must be broad in coverage yet specific in terminology so that the multidisciplinary and interdisciplinary nature of the epidemic is reflected. In respecting the dynamic nosological record of HIV/AIDS, the controlled vocabulary captures the societal construct circumscribing the pathological *(ibid.)*.

In the early years of diagnosis, the social construction of HIV/AIDS prevailed since it marked the attention of people by identifying homosexuals as the cause of rapid spread of AIDS. When the syndrome was identified among the Haitians, haemophiliacs, prostitutes and injecting drug users (IDUs), the stigma fears and negative imagery worsened but remained predominantly gay oriented. Many argue that the crisis appeared during a period of "moral panic", wherein traditional institutions were challenged with particular force and the cultural meanings of race, class, gender and sexuality were called into question. Therefore, AIDS provided an additional event to which society could attach its fears about the instability of the family, changes in the hierarchy of gender and sexual relationships and shifting access to economic privilege *(ibid.)*.

Near the beginning of the pandemic, mainstream media neglected AIDS, asserting that presumptively gay issues were not appropriate topics for the evening news and political responses were shaped by the perception that AIDS affected only small, unpopular groups. Early debates ignored policy questions about blood supplies, women's health or paediatric infection. Gay men were viewed as culprits to be stopped with a minimum of expense. But with the passage of time, a shift occurred in the social construction of HIV/AIDS as it demonstrated the draconian nature of the concrete human conditions. Though, the social construction did not change as much as it became stratified as new constructions were layered on the top of the old *(ibid.)*.

In the present paper, endeavour has been laid to understand the diverse pattern in which HIV/AIDS is being constructed within the family, community and society. It will emphasize on the association between subjective realities of the society *vis-a-vis* realities pertinent to people living with HIV/AIDS (PLWHA). Subsequently, it will also give a brief outlook on how varied social elements construct this illness which remains at variance from the objective and esoteric reality.

Route of Transmission

Route of HIV/AIDS transmission is considered as one of the most imperative variable to comprehend. Most of the global data reveal the fact that heterosexual contact is one of the leading

causes of HIV/AIDS worldwide. No doubt, homosexuality, particularly penetrative sex has also played a predominant role in fuelling this pandemic. From the early diagnosis of HIV/AIDS, many countries viewed this illness as 'Gay Plague'. Later on, other routes of HIV/AIDS transmission were discovered. Even after more than two decades, the psycho-social responses of the community member remain frozen as they are unable to act on the later discoveries pertaining to HIV/AIDS transmission. As a result, people who are diagnosed as sero positive are seen as promiscuous, particularly women who are always labelled as immoral and blamed for the rapid spread of this illness. Globally, four major routes are predominant through which HIV/AIDS can be spread from one person to another person. They are unprotected anal or vaginal sex, use of contaminated syringe, contaminated blood transfusion and finally from mother to child. The data collected in the present study has been presented in the table 1.

Table 1 : Distribution of Respondents According to Routes of Transmission

Responses	**Number**	**Percentage**
Unprotected Sex	101	33.66
Blood Transfusion	17	5.66
Intravenous Drug User	55	18.34
Men having sex with men	2	0.66
Family member infected	82	27.34
Needle Stick Injury	3	1.00
Treatment with contaminated syringe	40	13.34
Total	**300**	**100**

Table 1 reveals that more than one third of the total respondents mentioned that they contracted HIV/AIDS through unprotected sexual relations. 27.34 per cent contracted HIV/AIDS from their family members. Intravenous Drug Use route was mentioned by nearly 20 per cent. Nearly 15 per cent believed that they contracted HIV/AIDS through the use of contaminated syringe by the doctor. From the above table, it is clear that among the HIV positive respondents, majority said that they contracted HIV/AIDS through unprotected sex.

Uncertainty was shown by few respondents while disclosing their route of transmission during the research. It was noted that few respondents were not sure about their route of transmission, i.e. respondents mentioned that they are not sure whether they have contracted HIV/AIDS from a single route or more. These respondents mentioned two and in few cases more than two routes of transmission except to their primary route that is from unprotected sexual relations. Nevertheless, the respondents who mentioned unprotected sexual relations as their first vulnerable route of transmission were considered as their primary route of transmission during the research. It is also apparent that these respondents who claimed to have contracted HIV/AIDS through different routes are revealing the true picture of their personality. However, there is a possibility that these people are constructing a new societal image. Nevertheless, it is quite clear that they have expressed their first route of HIV transmission as unprotected sexual relation.

National AIDS Control Organization (NACO) conducted a study in 2003 which makes explicit that, the predominant mode of transmission of infection in AIDS patients is through heterosexual contact (85.29 per cent). Other modes of transmission are injecting drug use (2.87 per cent), blood transfusion and blood product infusion (2.99 per cent) and other (7.25 per cent). Males account for 74.88 per cent of AIDS cases and females 25.12 per cent with the ratio of 3:1 (Narain, 2004).

Another survey conducted by UNAIDS in year 2008 revealed that 87 percent of the HIV/AIDS worldwide is transmitted through unprotected sex. India's epidemic is largely a result of HIV transmission within, between and immediately beyond those most-at-risk populations. North-east states are vulnerable to HIV/AIDS transmission where contaminated drug injecting equipment is the key factor, HIV appears to be spreading mainly as a result of unprotected sex between sex

workers and their clients, and their respective other sex partners (AIDS epidemic update regional summary, 2008).

Sharing the Agony

After learning about the infection one is suffering, the immediate response would be to share it in anticipation of getting moral support. Research on disclosure of HIV status has focused primarily on telling sexual partners or family members (Gard, 1990; Holt, *et al.*, 1998; Mansbergh, Marks, & Simoni, 1995; Marks, Richardson, & Maldonado, 1991). Studies have shown that individuals who have not disclosed their HIV status feel isolated, depressed, anxious, and alienated (Crandall & Coleman, 1992; Van Devanter, Thacker, Bass, & Arnold, 1999).

In order to know the reactions and responses it was first decided to gather the information whether the respondents after knowing the results have shared it with their spouse, relatives, friends etc or not. The purpose was to find out that whether the respondents who were informed about their sero positive status have shared their agony with anyone. It was found that 65.66 per cent shared their agony with someone after getting their result and 34.33 per cent didn't share their agony with any one after getting their result. Various reasons were given by the respondents who shared their agony and who didn't share their agony. Following are the reasons mentioned by the respondents for disclosing and not disclosing their HIV positive results which have been presented in table 2.

Table 2 : Disclosure after getting HIV Positive Result

Responses	**Total**	**Percentage**
Shared		
Husband	64	32.48
Wife	41	20.81
Friend/s	3	1.69
Relative/s	22	12.42
Children	8	4.51
Parents	21	11.86
Parents (in laws)	28	15.81
Total	**197**	**100**
Did not share		
Afraid to disclose	39	37.86
My spouse will suspect me	40	38.83
Suicidal Ideations	7	6.79
I am all alone/ I have no one with me	17	16.50
Total	**103**	**100**

It is evident from the above table that 32.48 per cent respondents mentioned that they have shared their agony with their husbands and 20.81 per cent shared the agony with their wives. Respondents who find themselves reluctant to share their agony with someone after getting their HIV positive results gave various reasons. Among them, 38.83 per cent said that their spouse will suspect them if they will disclose their status and 37.86 per cent said that they were afraid to disclose the status because they felt that sharing can lead to affliction within the family.

The disclosure regarding the HIV positive status can also be made to acquire emotional support. It is imperative to have someone on your side during crisis to listen to your concerns, to offer suggestions, and to just simply be there. In some situations, helping with daily life chores or picking you up at a doctor's office are things that can also become important. Sometimes people fear becomes a burden when they have health problems. Actually, sharing these daily experiences can be seen as an opportunity for building a deeper intimacy and a stronger partnership (c.f. www.aidsmeds.com).

A study conducted by Kalicman *et al.* (2003) on Stress, Social Support and HIV Status Disclosure to Family and Friends among HIV positive Men and Women found that, most of the

participants disclosed their HIV positive status to some relationship members and not to others. Rates of disclosure were associated with social support. Friends were disclosed to most often and perceived as more supportive than family members, and mothers and sisters were disclosed to more often than fathers and brothers and perceived as more supportive than other family members.

Holt *et al.* (1998) found that immediately after post-diagnosis; individuals typically do not disclose and use avoidance and denial as mechanisms to respond to the diagnosis. Asymptomatic individuals who have begun to accept the diagnosis may disclose their HIV status as a coping mechanism to regain control over their lives and relieve the stress of not disclosing. When an individual becomes symptomatic or develops AIDS, disclosure is necessary to get medical services and social support. Holt and colleagues found that disclosing at this point was a positive experience for some individuals, but for others it was an unwelcome indication of the effects of the illness.

Wolitski *et al.* (1998) found that when individuals did disclose their HIV status, it was most frequently to significant others such as primary partners and friends, rather than to people considered to be less significant such as employers or co-workers. Green (1996) mentioned that, disclosure of HIV status is a double-edged sword, because it creates opportunities for medical and social support, which can be critical in adjusting to the illness, but it may lead to extra stress as a result of stigmatization, discrimination, and disruption of personal relationships.

Disclosure to the Spouse

A few studies have also shown that most HIV positive people disclose their HIV diagnosis to their significant other – their spouse or partner within a few days of learning their status. One approach that many follow is to consider that the only people you need to tell about your status are those who come in direct contact with your bodily fluids such as blood, semen, or vaginal secretions. Most immediately that means a spouse or partner. The HIV issue in relation to a significant other can be complex. If you have had unprotected sex with your partner, it is a matter of being attentive owing to the fact that they may have been at risk and should get tested. Second, regardless of your partner's decision to test and his or her results, you are now making them aware of the need for you both to practice protected sex together in the future (c.f. www.aidsmeds.com).

The respondents were asked that whether they have disclosed their HIV positive status to their spouse after getting their result. Amid the married respondents only 29 respondents mentioned that they have disclosed their status to their spouse while 182 respondents said that they have not disclosed their status. Various reasons were given for disclosing and not disclosing their HIV positive status to their spouse which are enlisted in the following table.

Table 3: Disclosure of HIV Positive Status to the Spouse

Responses	**Total**	**Percentage**
No		
My spouse will suspect me of having sexual relation outside marriage	17	58.62
She will refuse to have sex with me	12	41.37
Total	**29**	**100**
Yes		
Accompanied by Spouse	74	40.65
Wanted to get spouse tested	72	39.56
Spouse already knows my HIV status	31	17.03
Emotionally attached to my wife	5	2.74
Total	**182**	**100**

Table 3 depicts that among those who didn't disclosed their status to their spouse, 58.62 per cent said that their spouse will suspect them of having sexual relations outside marriage and 41.37 per cent mentioned that their spouse will refuse to have intercourse with them. Among those who disclosed their status to their spouse, 40.65 per cent said that they were accompanied by their spouse

while going for HIV test and 39.56 percent said that they wanted to get their spouse tested and that is why they disclosed their status to the spouse.

Kalichman & Nachimson (1999) found that, Individuals who did not disclose to sexual partners demonstrated greater psychological effects and were described as showing signs of somatic anxiety, hostility, and phobic anxiety.

From the above table, it is crystal clear that most of the respondents disclosed their status to their spouse and very few did not disclose the status to their spouse. It can be due to the emotional concern and social responsibility shown by the respondents for their partner since most of them have to look after their progeny.

Disclosing to the Family Members

A study conducted by Asia Network of People living with HIV/AIDS (2004) shows that, 'After diagnosis, few of the sample experienced some discrimination from their family, some were excluded from usual household activities such as cooking, sharing food and sleeping in the same room as other family members. Women were significantly more likely to be excluded from usual household activities than men were, often by in-laws. When people experienced discrimination from their family, it was not an isolated incident but tended to be a frequent or continuous occurrence. Respondents those who reported coerced testing were significantly more likely to experience discrimination from family members in lieu of those who did not report coerced testing. Various reasons were mentioned by them for not disclosing their status to family members.

In the present study, an effort has been made to know about the respondents who unveil their positive status to family members and those who did not disclose their status. It was found that 78.34 per cent have disclosed their status to their family members and 21.66 per cent said that they have not disclosed their status. Various reasons were given for disclosing and not disclosing their HIV positive status to their family members which have been presented in table below.

Table 4 : Disclosure to the Family Members

Responses	**Total**	**Percentage**
Yes		
Accompanied by family members	83	35.31
Spouse died of AIDS	61	25.95
Due to financial assistance from family	44	18.72
Disease is curable	17	7.23
They know that I am a drug addict	30	12.76
Total	**235**	**100**
No		
They will start discriminating me	8	12.30
Family members are very old	17	26.15
They won't give me property rights	19	29.23
They will make fun of me	12	18.46
Children are very young to understand my problems	9	13.84
Total	**65**	**100**

Table 4 depicts that 35.31 per cent mentioned that they were accompanied by their family during HIV test, 25.95 per cent said that their spouse died of HIV/AIDS and 18.72 per cent said that they have disclosed their status to obtain some financial assistance. Among the respondents who did not disclose the status, 29.23 per cent said that their family members will not grant them property rights. During the research, it was also observed that majority of respondents residing in joint families mentioned fear of losing legitimate property rights. Meanwhile, 26.15 per cent said that the family members are aged and therefore revealing their status might lead to their physical and mental suffering.

Reaction of the Family Members

Most of the individuals suffer orthodox reaction from their family members after disclosing their sero-status. Primarily, it can be due to the lack of appropriate knowledge and information about this pandemic or due to the ignorance, prejudice and neglection pertaining to the issue of HIV/AIDS. Since the long term association of HIV/AIDS with sex, sexuality and promiscuity, individuals diagnosed with HIV/AIDS are often linked with immoral deeds and false practices.

Only 6 percent of the respondents said that their family members supported them after disclosing HIV positive status to them. Among those respondents who disclosed the status to their family members, a large number of respondents among them, i.e. 90 respondents (38 per cent) said that their family members were shocked when they came to know about their HIV positive status, 60 (26 per cent) mentioned that they were blamed by the family after learning their HIV positive status. Out of the total respondents who revealed their status to their family members, 26 (11 per cent), 24 (10 per cent) and 20 (9 per cent) respondents reported that their family members reacted in crying spells, fear of death and got surprised respectively after knowing the HIV positive status of their family member.

Behaviour Change among the Family Members

Change is the pre requisite of human nature. All the Homo sapiens have an innate potential to alter their behaviour and actions in accord to the prevailing circumstances. This innate potential of humans has led to devastating impact within the family. A large number of respondents, when asked replied that the behaviour of their family members was instantly changed after discovering the sero-status. A variety of reasons were mentioned by the respondents.

Table 5: Change in the Behaviour of the Family Members

Responses	**Total**	**Percentage**
Discriminated with me	42	17.88
They suspect me of having sexual relation outside the family	40	17.03
Comments me	39	16.59
Don't talk / Don't share food / Don't share kitchen	37	15.74
I feel that as if I am a burden on them	35	14.89
Avoid me	22	9.36
More concerned than earlier	20	8.51
Total	**235**	**100.00**

Table 5 depicts that nearly 18 per cent said that after discovering the HIV positive status, their family members have started discriminating with them, 17 per cent reported that their family members have started suspecting them of having sexual relations with someone outside the family, Nearly 17 per cent illustrated that their family members have began to pass filthy comments on them. Few respondents also mentioned that their family members don't talk/don't share food/don't share kitchen with them. They anticipated, '*I am burden on them*' and '*started avoiding me*' as mentioned by the respondents. Therefore, it is apparent from the above table and remarks given by the respondents on the social conduct, most of them were discriminated by their family members.

A study conducted by Asia Network of People living with HIV/AIDS (2004) also shows that after diagnosis, 18 per cent of the sample experienced some discrimination from their family; 14 per cent were excluded from usual household activities such as cooking, sharing food or eating implements or sleeping in the same room as other family members. Women were significantly more likely to be excluded from usual household activities, than men often by their in-laws. When people experienced discrimination from their family, it was not an isolated incident but tended to be a frequent or continuing occurrence.

Conclusion

It can be depicted from the above mentioned facts that individuals enormously construct the reality based on HIV/AIDS. Men at large construct HIV/AIDS and most of them don't find it suitable to reveal their status to their spouse. But in contrast, women in particular find it more suitable to disclose their status to their husbands. The reasons for this could be due to economic dependence on their husbands or due to the health concern of their spouse. Further, the paper shows that most of the people who come for HIV testing are accompanied by their family members. It shows their dependency on their family members. But ironically, few people think that the family members should not be accompanied during the HIV test because it may lead to family disharmony. Similarly, many respondents do not accept the fact of disclosing their status to their family members as it may lead to anxiety. Non disclosure is also made fearing the factor of discrimination within the family. Few respondents also believe that the family members will restrict the possession to the property.

It also illustrates that not many respondents revealed their status to their friends as they fear that their friends will start discriminating them. The respondents who disclosed their status to their friends are mainly truck drivers, police personals, prisoners and Intravenous Drug Users who are either sharing the same place of residence or are from the same profession and due to the cordial alliance, they find it comfortable to disclose their status to the friends. Another reason which has been found that while they are together, they intake ART *(Anti Retroviral Therapy)* and the friends nearby do ask that why are you taking this medicine. Many people at that time do disclose their status to the friends in order to gain some mental strength. But after disclosing the status not many people get moral support from their friends as they giggle behind their back.

The present paper also highlights that not many respondents reveal their status to their community members because they fear the isolation and discrimination toward them and their family members within the community. Among those who reveal their status suffered from innumerable problems from the community members. Few of them were not invited to the local gathering within the community because they fear the illness and think that the community will get infection from them. Another reason which can be highlighted here is that the community members feel that their social status will lower down if they will invite any HIV positive person in the local gathering.

Among those who are invited on the social gatherings often face discrimination and filthy commenting from the community members. The study shows that the respondents are not comfortable to reveal their status within the society as they fear the discrimination and commenting. Moreover, they also give a wicked look to the person and pass moral judgments on the character. The study also shows that people don't share their status with their colleagues as they fear that it can result into multifaceted problems within their place of work. Moreover, there is also a fear of being fired from the job by the employer.

It can be discerned evidently that the people living with HIV/AIDS interface social, psychological and financial problems due to their illness. They remain under cover from their family, community and society at large fearing the discovery of newly constructed ideas that are result of their own prejudices and stereotypes.

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