

# Acceptability of HIV Pre-Exposure Prophylaxis Among Transgender Women in India: A Qualitative Investigation

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## Abstract

Despite high HIV prevalence among transgender women (TGW) in India, there is limited exploration of pre-exposure prophylaxis (PrEP) acceptability. With PrEP licensure pending, we conducted six focus group discussions (FGDs) with diverse TGW ( $n=36$ ), and eight key informant interviews with community leaders and physicians, in Mumbai and Chennai. Data were explored using framework analysis guided by the Theoretical Framework of Acceptability. FGD participants' mean age was 26.1 years ( $SD=4.8$ ); two-thirds engaged in sex work. TGW reported low PrEP awareness, with moderate acceptability once PrEP was explained. Population-specific facilitators of PrEP acceptability included its perceived effectiveness in the context of challenges to condom use in serodiscordant relationships and forced sex encounters. PrEP was considered especially appropriate for TGW sex workers; however, barriers were anticipated in the context of hierarchical *hijra* (indigenous trans identity) kinship networks and *gurus*' (masters) potential negative reactions to PrEP use by their *chelas* (disciples). Positive attitudes toward high efficacy and potential covert use were tempered by TGW's concerns about high costs and adherence challenges living with parents or primary partners, and TGW sex workers' unpredictable schedules. Anticipated interactions with feminizing hormones, visible side effects, and PrEP-related stigma within TGW communities emerged as opportunity costs. PrEP implementation for TGW in India should promote comprehensive information on side effects and potential interactions with feminizing hormones, provide free or subsidized PrEP, and highlight the advantages of added protection in sex work and forced sexual encounters. Meaningful engagement with TGW kinship networks can encourage positive transgender community norms on PrEP use and mitigate multifaceted stigma.

**Keywords:** PrEP, HIV prevention, transgender persons, sex workers, India

## Introduction

**T**RANSGENDER WOMEN (TGW) in India—with the third highest national HIV prevalence globally—are disproportionately affected by HIV.<sup>1</sup> National HIV prevalence among TGW in India is estimated at 7.5%, with wide variations by site: 12.1% (95% CI 8.2–17.5) in Mumbai, 8.2% (95% CI 2.3–25.5) in Chennai, and other cities as high as 23.0%.<sup>2</sup> As in HIV epidemics in other countries, the overrepresentation of TGW is a function of pervasive discrimination and violence, including rampant sexual violence, lack of educational and employment opportunities, and wide-

spread engagement in sex work.<sup>2–4</sup> From one-third to two-thirds of TGW in India are estimated to engage in sex work.<sup>2</sup>

India's National AIDS Control Programme offers targeted HIV interventions for key populations, including TGW, and provision of free condoms. Despite over a decade of condom promotion and distribution, nearly half of TGW report inconsistent condom use; more than 90% engaged in anal sex; and two-thirds had a paying partner in the past year.<sup>2</sup> These data strongly indicate the need for expanded approaches to prevent HIV infection. Oral HIV pre-exposure prophylaxis (PrEP) is highly (>90%) effective in reducing the risk of contracting HIV through condomless sex.<sup>5,6</sup> Recent trials

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have shown intermittent and event-driven PrEP regimens to be equally effective as daily PrEP.<sup>7,8</sup> Based on a preponderance of evidence, the World Health Organization recommends PrEP for most at-risk populations, including TGW, as part of combination HIV prevention approaches.<sup>5,9</sup>

Despite a concentrated HIV epidemic among TGW in India, we identified no published studies of PrEP acceptability among this population. Investigations among men who have sex with men (MSM)<sup>10</sup> and female sex workers<sup>11</sup> in India indicate high PrEP acceptability, with concerns about stigma and side effects. Limited research with TGW in China, Vietnam, and Thailand has demonstrated low PrEP awareness and low-to-moderate acceptability (37–61%).<sup>12–14</sup> Given the slow uptake of PrEP internationally, and its pending licensure in India, it is crucial to explore and understand PrEP acceptability among TGW.<sup>15</sup>

A recent systematic review proposed a model of acceptability of health interventions, the Theoretical Framework of Acceptability (TFA).<sup>16</sup> We chose TFA to guide exploration of PrEP acceptability among TGW as it can readily incorporate community-level influences on attitudes and behavior, in contrast to more individual-level cognitive models, such as the Integrated Behavioral Model used in a US study of PrEP acceptability among transgender adolescents.<sup>17</sup> According to TFA,<sup>16</sup> intention to use a health intervention is determined by seven factors: (1) *perceived effectiveness*—the extent to which the intervention is seen as likely to achieve its purpose; (2) *intervention coherence*—participant's understanding of the intervention and how it works; (3) *affective attitudes*—feelings about the intervention; (4) *burden*—perceived effort required to participate; (5) *ethicality*—fit with individual's value system; (6) *self-efficacy*—confidence in performing the behavior(s) required to participate; and (7) *opportunity costs*—what benefits must be given up to participate.

Given the lack of research on PrEP acceptability among TGW in India, we conducted a qualitative study guided by TFA to explore PrEP awareness and acceptability from the perspectives of diverse TGW, including those in sex work. The goal is to inform forthcoming PrEP education and implementation programs for TGW in India.

## Methods

Under the broadly accepted modern terminology of “transgender,” trans women in India have a 1000-year history<sup>18</sup> and many indigenous identities.<sup>4</sup> These include *hijras* in northern/western India and *thirunangai* in Tamil Nadu. Some subgroups (e.g., hijras) are organized into *gharanas* (clans) with extensive kinship systems (outside the traditional family) and their own hierarchical social structure, with *gurus* (masters) guiding their *chelas* (disciples). These social structures and community dynamics are integral to understanding sexual practices, and to designing and implementing effective combination HIV prevention.<sup>15</sup>

From April to June 2017, we purposively sampled diverse TGW (including *hijras* and *thirunangai*) recruited in collaboration with community-based organizations (CBOs) in Chennai (*Thozhi*) and Mumbai (The Humsafar Trust). Chennai, the largest city in Tamil Nadu, has an estimated population of 10 million; Mumbai, Maharashtra, with ~24 million people, is among the most populous cities in the world. Four focus group discussions (FGDs) (Mumbai [2],

Chennai [2]) were conducted with TGW who engage in sex work, and two FGDs (Mumbai [1], Chennai [1]) with TGW not engaged in sex work. Inclusion criteria were as follows: ≥18 years old, self-identified as a transgender woman (any indigenous trans identity), and able to provide written informed consent. Recruitment was conducted by word-of-mouth through trained peer recruiters of CBOs. FGDs were 1 h in duration. In-depth key informant (KI) interviews were conducted with physicians and TGW community leaders in Chennai and Mumbai, purposively selected based on experience on TGW and PrEP.

Ethics approvals were obtained from the Institutional Review Boards of the University of Toronto (30607) and The Humsafar Trust (37-12/2016). FGD participants received INR 300 (~ \$5 US) compensation. KIs were not paid.

## Data collection

A semistructured FGD topic guide<sup>19</sup> explored prior awareness about PrEP, willingness to use PrEP, barriers and facilitators to PrEP uptake, preferences for access venues and pricing, and anticipated change in condom use. FGDs and KI interviews were conducted by trained interviewers in participants' native languages (Tamil, Chennai; Hindi or Marathi, Mumbai); two physician interviews were conducted in English. After assessing prior PrEP awareness, FGD facilitators provided a brief description of PrEP, based on AIDS Vaccine Advocacy Coalition<sup>20</sup> and US CDC information sheets,<sup>21</sup> and PrEP efficacy greater than 90%.<sup>5,6,9</sup> Facilitators responded to questions to ensure common understanding of PrEP, and explored perspectives on alternative dosing regimens (i.e., event-driven/intermittent use)<sup>22–24</sup> and their impact on acceptability.

## Data analysis

FGDs and interviews were digitally recorded, translated into English, and explored using framework analysis.<sup>25</sup> A codebook was developed with *a priori* codes based on TFA constructs, our topic guides, and research on PrEP acceptability.<sup>10,13</sup> Emergent codes/categories identified from the text were added to the codebook and used for further coding, with differences in coding/categorizing resolved by consensus.<sup>26</sup> Methodological rigor was supported through data source triangulation<sup>26</sup> between FGDs and KI interviews, and member checking<sup>27</sup>—findings were discussed with trans community leaders and service providers and their feedback integrated.

## Results

### Sociodemographic characteristics

FGD participants' ( $n=36$ ) mean age was 26 years. About two-thirds had completed high school or college and two-thirds reported sex work as their main occupation (Table 1). About one-fourth identified as hijra and 47.2% as thirunangai. Nearly one-third reported inconsistent condom use in the past month. Among eight KIs, five were trans community leaders, and three were cisgender male physicians. Findings are reported across seven themes with representative quotations.

### Perceived effectiveness

Overall, FGD participants (except for one) had never heard of PrEP. After facilitators explained PrEP efficacy >90%,

TABLE 1. SOCIODEMOGRAPHIC CHARACTERISTICS OF TRANSGENDER WOMEN IN FOCUS GROUPS (N=36)

	Overall sample (N=36)
Age, years	
Mean	26.1
SD	4.8
Monthly income, INR	
Mean	12,245
SD	6066
Highest level of completed education, n (%)	
<High school	14 (38.8)
High school/higher secondary	11 (30.5)
College degree	11 (30.5)
Main occupation, n (%)	
Sex work	24 (66.7)
<i>Mangti</i> (begging or asking for money from shops)	9 (25.0)
Self-employed	3 (8.3)
Primary identity, n (%)	
<i>Hijra</i>	9 (25)
“Transgender”	8 (22.2)
<i>Thirunangai</i>	17 (47.2)
Woman	1 (2.8)
“CD”	1 (2.8)
Current living situation, n (%)	
Living alone	7 (19.4)
Living with parents	12 (33.3)
Living with <i>guru/chela</i> (master/disciple)	6 (16.7)
Living with peers	11 (30.6)
Consistent condom use, past month, n (%)	
No	11 (30.6)
Yes	25 (69.4)

CD, cross-dresser; SD, standard deviation.

most TGW reported that it was a useful HIV prevention method. PrEP was described as: “extra safe”—offering additional protection if used with condoms; “safe if one of the couple is positive”; and useful in instances of “forced sex by police or goondas” or of alcohol use before sex in which condom use is unlikely. A minority of participants reported that the high effectiveness of PrEP means that TGW, especially those who are young, would reduce or stop using condoms: “Since they think, ‘I am already on [PrEP]’...this (condomless sex) will definitely happen...if customers offer them more money” (FGD-1, Mumbai). In particular, participants explained that young TGW in sex work would stop using condoms as they need money for sex reassignment surgery. Health care providers emphasized that PrEP users should be counseled on the need to continue using condoms: “Clients will think, ‘why doctors tell us to use both condoms and PrEP?’ We should adequately explain it in counseling.”

#### Intervention coherence

Intervention coherence requires that TGW perceive themselves at risk so they understand PrEP as appropriate. Participants largely indicated understanding PrEP as useful, especially for high-risk TGW: “We need to identify people who give gaans (engage in receptive anal sex) and ask them to

take PrEP...they are the ones who are at high risk” (FGD-3, Chennai). While most TGW reported that PrEP would be acceptable to TGW in sex work, a few expressed concerns that prevalent alcohol use among TGW may interfere with adherence.

Challenges to intervention coherence were indicated for TGW in certain gharanas (clans), seen as unlikely to use PrEP: “Many hijras in mangti (begging) do engage in sex work but they don’t have much knowledge about staying safe from HIV. It will be difficult to convince them as they would not even admit they are in dhanda (sex work), fearing punishment from their gurus” (FGD-3, Mumbai). Some TGW indicated that those who had undergone vaginoplasty do not need PrEP: “This tablet will be only useful for those who have anal sex. We are operated and we prefer doing it front [vaginal sex] or by mouth. Those like us don’t prefer back sex” (FGD-3, Chennai). Intervention coherence may be challenged for some high-risk TGW due to social and behavioral contexts that present obstacles to PrEP acceptability.

#### Affective attitudes

Participants generally expressed positive attitudes toward PrEP, citing its key role in decoupling sex from anxiety. PrEP’s high efficacy and the ability to use it covertly, as in sex work, where condom use is challenging, enhanced positive attitudes. A KI explained: “Let’s say if I am going for sex work and I eat it 2 hours before leaving, and if it still gives me more than 90–95% protection, then I will surely use it” (KI, TGW-leader, Mumbai). Participants indicated the advantages of covert PrEP use in providing protection when condoms break, when partners refuse to use condoms, and in instances of forced sex by police or thugs.

#### Burden

Burdens of PrEP use were described in terms of cost, adherence to a daily regimen, and hiding PrEP from family members. Most TGW preferred free or subsidized PrEP, reasoning that sex workers with less income would not be able to afford it. Daily PrEP use was described as a burden, particularly for TGW in street-based sex work due to the unpredictability of their schedules: “We go out in night and come back home early morning. We don’t even know when we will wake-up or when we will prepare our food and eat; so we can’t take pills on time” (FGD-1, Chennai). FGD participants and KIs expressed the need for intermittent or event-driven PrEP in India, with some indicating preferences for long-acting injectable PrEP. Amidst broader stigma against TGW, participants living with parents or a male lover expressed concern about keeping PrEP use secret—to avoid suspicions of being a sex worker, a “drug addict,” or “diseased”: “Accepting us as trans woman itself is a big thing in our family...if they come to know that I am taking some tablets daily they will wonder why I am doing so and start avoiding us” (FGD-2, Chennai).

#### Ethical concerns

PrEP use was reportedly aligned with most TGW’s values, with overall benefits seen to outweigh harms. Ethical concerns arose around covert use, side effects, and PrEP stigma. Although the ability to use PrEP covertly was seen as an

advantage by some, others expressed concern about the ethics of hiding PrEP use from primary male partners and worried about partner reactions if they found out. Both FGD participants and KIs reported concerns about side effects; however, TGW reasoned in light of their tolerance for hormone use that they would use PrEP as long as the side effects were minor and of limited duration, given its benefits: “If the side-effects last for only two days, then everybody will take. When we start taking hormones we have giddiness...body feels heavy...we don’t get sleep. That doesn’t stop us from taking hormones” (FGD-2, Mumbai). Some KI providers expressed concerns about PrEP causing harm to otherwise healthy persons. Both KIs and FGD participants indicated the importance of TGW being adequately counseled by health care providers about possible side effects. Finally, KIs explained that labeling TGW as “high risk” and prioritizing them for PrEP programs were problematic, even unethical. A health care provider argued: “Why we need to increase the stigma faced by trans women and some other groups by saying PrEP is needed for them. Why can’t we say for anyone at risk for HIV, PrEP is an option?”

### *Self-efficacy*

Both FGD participants and KIs expressed concerns about TGW’s ability to adhere to a daily regimen and to initiate conversations about PrEP with male primary partners. TGW reported that it might be challenging for high-risk TGW to initiate PrEP as they do not even take presumptive treatment for common bacterial sexually transmitted infections: “When we go for our HIV testing we get 2 pills [antibiotics] there; but we don’t take them. You will find those pills in the gutter” (FGD-1, Mumbai). Health care providers expressed similar concerns: “In my center, TGW are not very regular in taking ART. So, it will be even more challenging to make TGW who don’t have HIV understand the need for PrEP and take it regularly.”

### *Opportunity costs*

Opportunity costs of using PrEP were identified in potential side effects, particularly visible effects that interfere with beauty, potential interactions with feminizing hormones, PrEP-related stigma, and venues to procure PrEP. A KI explained that as TGW have seen visible side effects (e.g., sunken cheeks) of long-term antiretroviral use among HIV-positive TGW, they would hesitate to take PrEP: “They will work hard not to eat but to earn money for beauty–fairness creams, hair creams and hormones. If this tablet affects their beauty they will not take it” (KI, Trans community leader, Mumbai). Most FGD participants expressed concerns about interactions between self-prescribed hormones and PrEP: “We are already taking tablets for breast development. Although PrEP is meant to protect us from HIV, all these tablets will get mixed in our blood...we worry about drug interactions... Will it produce any reactions like hair loss, skin damage or kidney failure?” (FGD-3, Chennai).

The context of TGW’s social networks emerged as a particular opportunity cost in anticipated discrimination from gurus if they found out TGW were taking PrEP; however, others thought that gurus would be more accepting: “The gurus of these days have moved ahead with time. They know that their chelas (disciples) are into sex work and are thus at

risk. So, they would ask their chelas to take care of themselves” (KI, Trans community leader, Mumbai). TGW also expressed concern that if other TGW saw them taking “those anti-HIV pills” they could be mistaken as being HIV positive, or a sex worker, thus detracting from PrEP acceptability: “In our community, if someone sees that a person is taking same pill from the same box regularly then they would immediately ask...‘Do you have you the big clap or a small clap?’ (HIV or STI)” (FGD-1, Mumbai). Fear of rejection by parents and male lovers if they discover TGW’s PrEP use emerged as another opportunity cost.

Fear of being labeled HIV positive and fear of discrimination were reflected in preferred venues to access PrEP. TGW participants and community leaders expressed discomfort with private pharmacies due to anticipated transphobia and PrEP stigma, and public hospitals “due to the travel fare and the long queues there” (KI, Trans community leader, Mumbai), and inflexible hours. CBOs were described as reducing opportunity costs: “If this is provided by CBOs...for like a month or 14 days, then they can collect it at one go” (KI, Trans community leader, Mumbai); “Definitely, yes!...PrEP can be provided by NGOs so that people don’t have to join ART queues [in public hospitals] and be mistaken as HIV-positive...so that they won’t feel this stigma” (Health care provider, Mumbai).

## **Discussion**

In this qualitative study, among the first investigations of PrEP acceptability for TGW in India despite their disproportionate HIV infection burden, we identified very low PrEP awareness. Once basic information on PrEP was provided, most participants expressed broad acceptability—similar to that documented among MSM<sup>10</sup> and female sex workers<sup>11</sup> in India. Nevertheless, we identified multifaceted transgender- and culture-specific challenges to PrEP acceptability, highlighting the importance of community-based, culturally sensitive exploratory research and tailored strategies to support effective PrEP implementation.

Using the TFA<sup>16</sup> as an organizational schema, we discerned TGW-specific challenges to PrEP acceptability across seven domains (Table 2). The perceived effectiveness of PrEP, beyond its high efficacy, was amplified in the context of a population subject to an epidemic of sexual violence, including risks of sex work<sup>3,4,28</sup> and from male primary partners.<sup>28,29</sup> PrEP was seen as supplementing protection from condoms, given the all too common instances of forced sex among TGW. The construct of intervention coherence, the perceived population appropriateness of PrEP, highlighted the relevance of PrEP for TGW, many of whom engage in sex work; however, challenges to coherence emerged in the context of hierarchical TGW community kinship networks outside families of origin and anticipated negative reactions among hijra disciples from their gurus.

Affective attitudes were positively influenced by PrEP’s high efficacy and potential for covert use, a benefit in paid sex encounters and with primary partners, for whom condomless sex may represent love and commitment.<sup>15,29</sup> Studies among TGW in Myanmar<sup>30</sup> and China<sup>12</sup> similarly revealed the importance of perceived support from male primary partners to PrEP acceptability. Burdens arose in the anticipated high cost of PrEP and adherence challenges, including keeping PrEP

TABLE 2. PRE-EXPOSURE PROPHYLAXIS ACCEPTABILITY AMONG TRANSGENDER WOMEN IN INDIA

<i>Theoretical Framework of Acceptability</i>	<i>Findings</i>
Perceived effectiveness	Additional protection to condoms Protection in HIV serodiscordant relationships Effective in forced sex encounters and others in which condoms are unlikely to be used
Intervention coherence	Appropriateness of PrEP for TGW in sex work and those with multiple partners Expressed need for trans community leaders' support
Affective attitude	Anxiety-free sex Perceived advantages (e.g., if condoms break) Ability to covertly use PrEP
Burden	High cost of PrEP Daily use/adherence
Ethical concerns	Hiding PrEP use from family/partners/peers Side effects should be minimal and of short duration Labeling certain groups as eligible for PrEP was perceived to exacerbate PrEP-related stigma
Self-efficacy	Ability to adhere to a daily regimen Discussing and revealing PrEP use with primary male partner
Opportunity costs	Side effects (that may impact on physical beauty) Fear of interactions with feminizing hormones PrEP-related stigma in TGW communities

PrEP, pre-exposure prophylaxis; TGW, transgender women.

secret in living situations with parents or primary partners. The construct of self-efficacy underscored concerns about the ability to navigate adherence amidst TGW sex workers' unpredictable schedules and to initiate discussion of PrEP with primary partners. Perceived challenges in adherence to a daily regimen similarly arose among TGW in the United States,<sup>17,31</sup> with a preference for long-acting injectable PrEP to reduce adherence burden.<sup>32</sup>

TGW-specific opportunity costs of PrEP included potential interactions with often self-prescribed feminizing hormones and anticipated visible side effects that impact on physical beauty—a salient concern given its association with core identity as a (trans) woman and earning potential from sex work. Fear of harmful interactions between PrEP and feminizing hormones similarly emerged among TGW in the United States,<sup>28</sup> as in the context of ART adherence among TGW in Canada.<sup>33</sup> Given recent findings suggesting that feminizing hormones have the potential to negatively impact PrEP efficacy,<sup>34</sup> it becomes crucial that clinicians provide accurate information and take appropriate precautions, such as conducting relevant follow-up tests along with possible dose adjustment.

Pervasive opportunity costs revolved around anticipated PrEP stigma within close-knit TGW communities—being labeled a sex worker or “promiscuous”—and in public venues for PrEP access in which TGW are already stigmatized. Concerns around sex shaming by peers detracted from PrEP acceptability among TGW in the United States,<sup>35</sup> and MSM in Canada.<sup>36</sup> In India, where hijras largely do not receive support from their biological families but rely on peers as a bulwark of emotional and psychological support,<sup>15,37</sup> anticipated stigma may factor strongly into PrEP acceptability. In certain gharanas (clans) of hijra communities,<sup>15</sup> even discussing condom use is taboo. From a cultural lens, these opportunity costs highlight the importance of engaging and collaborating with hijra community leaders and pro-

moting positive TGW community norms about PrEP to support implementation.

Our results should be interpreted in light of study limitations. As a qualitative investigation, our aim was not to generalize, but to explore, in-depth perspectives of TGW; however, we successfully recruited diverse TGW in terms of age, living arrangements, and sex work involvement in two large Indian cities. While our recruitment was conducted in collaboration with CBOs engaged in HIV prevention, future studies should recruit TGW through social media and dating apps to explore additional perspectives. As with any product, PrEP acceptability may shift as PrEP uptake increases among trans communities in India. Despite these limitations, we identified diverse community stakeholder perspectives on PrEP acceptability informed by a theoretical framework, along with potential barriers and facilitators, many of which are (trans)gender and culture specific—a benefit of qualitative methods.

Prospective acceptability studies among TGW, such as the present study, should inform the next phase of PrEP implementation in India, including demonstration projects to understand the real-world acceptability and feasibility of providing PrEP to TGW,<sup>38</sup> and phased introduction of PrEP in national HIV programs. Our findings suggest that comprehensive information on PrEP, including effectiveness, adherence, and side effects, should be tailored for TGW, with information about any potential interactions with feminizing hormones. CBOs that serve TGW may be important resources for guidance on adherence and discussing PrEP with significant others, including individual counseling and group forums, and through social media widely used by TGW in India.<sup>39</sup> Varied PrEP delivery models for TGW should be tested in India, including free or subsidized PrEP through CBOs and through antiretroviral centers in public hospitals, and intermittent or event-driven PrEP regimens.<sup>22</sup> Training and sensitization of health care providers on PrEP, and TGW health issues and gender-affirming care,<sup>33,40,41</sup> are central to

supporting PrEP implementation. Further, a recent US study identified a role for community mobilization strategies in increasing PrEP use among TGW.<sup>41</sup> In India, the close-knit kinship structures integral to TGW social support and community survival provide pivotal opportunities for mobilizing positive community norms about PrEP use and mitigating PrEP stigma; interventions that meaningfully engage with these culture- and gender-specific contexts may support successful PrEP implementation.

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### Authors' Contributions

V.C. and P.A.N. conceptualized and designed the study, and acquired funding. M.S., R.N., S.R., and D.B. conducted data collection and data analysis. V.C. critically reviewed data analysis and drafted the initial article. P.A.N. revised the article in its present form. All authors made contributions to interpretation of data, critically reviewed the article for important intellectual content, and gave final approval for the article in its present form.

### Author Disclosure Statement

No competing financial interests exist.

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