

HIV counselling and testing experiences of expectant mothers in the prevention of vertical transmission programme: implications for policy and service delivery

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Abstract

Objectives: This study explored the HIV counselling and testing (HCT) experiences of women who were diagnosed positive in the current pregnancy in a district hospital within the Sekondi-Takoradi Metropolis in Ghana following the implementation of the 'opt out' testing policy.

Methods: Adopting a qualitative explorative descriptive design, 12 mothers were sampled purposively and in-depth interviews were conducted. Thematic analysis using Colaizzi's approach was applied to unearth the experiences of the participants.

Results: Three key themes emerged: *The Pre-test Counselling Experience*; *The Test*; and *After Talk: Post-test Counselling*. Provider-initiated testing was offered to all the participants at antenatal booking. Most counsellors were silent about the 'opt-out' option of testing while pretest counselling focused on preventing vertical transmission and not on the health of the woman. Attitudes towards pretest counselling was mainly indifference or anxiety which affected the women's initial acceptance of a positive result. All the women took a confirmatory test after the initial positive results which aided them in accepting their diagnosis. Of the women who tested, all received post-test counselling that focused on enrolling on antiretroviral therapy (ART).

Conclusion: Attitudes towards pretest counselling impacts the mothers' reaction to a positive test result. HIV counselling that does not solicit voluntary testing may be effective in increasing testing but may affect uptake of treatment. It is recommended that midwives providing HCT be trained periodically to enhance service delivery while focus on women-centred care and improving women's agency in the prevention of vertical transmission services should be the paramount.

Keywords: experiences, Ghana, HIV counselling and testing, prevention of vertical transmission

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Introduction

Although great strides have been achieved since the first case was diagnosed, HIV continues to be a public health concern globally. By the end of 2020, approximately 36 million adults were living with HIV and 53% of these persons were women and girls. Of this number, 63% of all new infections in 2020 were recorded in sub-Saharan

Africa alone.¹ Ghana recorded a prevalence rate of 1.69% among the general population and 2.4% among pregnant women in 2020.² The country was also rated as having the second and fourth highest burden of vertical transmission in West Africa and among the 22 countries most burdened by HIV, respectively.³ To halt and reverse this trend, Ghana adopted the prevention of

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vertical transmission programme as one of the strategies to prevent, as well as identify and treat women and babies infected with HIV.⁴

In Ghana, prevention of vertical transmission interventions is delivered as an integrated programme within the existing Maternal New-born and Child Health (MNCH) services.⁵ The prevention of vertical transmission services is provided across antenatal care, labour and delivery care, as well as postnatal care up to 18 months.⁴ HIV Testing and Counselling (HCT) is routinely offered to all pregnant women as part of the initial antenatal care (ANC) service, and a repeat test is offered in the third trimester to women who initially test negative. The policy on HIV testing allows for both provider- and client-initiated testing and counselling.^{5,6} Opportunities for HCT are available along the prevention of vertical transmission cascade for women with undocumented HIV status during labour and postpartum.⁵

In 2015, the country transitioned from the treatment option B to B+ that ensures lifelong treatment of all clients enrolled in the prevention of vertical transmission programme.⁴ The preferred antiretroviral therapy (ART) regimen in Ghana is the triple fixed-dose formulation. Vaginal delivery is recommended, and antiretrovirals (ARVs) are administered during labour and delivery in accordance with national protocols.⁴ Caesarean delivery is considered on obstetric grounds rather than solely for preventing vertical transmission.

Postnatal care for HIV-positive mothers and exposed infants is synchronized and usually occurs within 3–7 days after birth and at 6 weeks postpartum for MNCH/Child Welfare Clinic (CWC) and prevention of vertical transmission services. The duration of infant follow-up depends on when HIV infection status is determined and on feeding method at the time. Exclusive breastfeeding or commercial infant formula milk for 6 months is recommended for exposed children. Mixed feeding is strongly discouraged.⁴

All exposed infants receive ARV treatment from birth until 6 weeks of age when the Early Infant Diagnosis (EID) is done using dried blood spot (DBS) for deoxyribonucleic acid polymerase chain reaction (DNA PCR). If the initial HIV DNA PCR is negative at 6 weeks, the infant is discharged from the prevention of vertical transmission follow-up programme and referred to

continue with the usual CWC programme. For breastfed infants, the test is repeated 6 weeks after complete cessation of breastfeeding for a definitive evaluation of the infant's HIV status. In places where the DNA PCR machines are unavailable, a serological test to determine the infant's status is done at 18 months or 12 weeks after complete cessation of breastfeeding. A positive serological test at 18 months means the child is positive and receives comprehensive HIV care and ART for life. All these services are free of charge.⁴

This article presents one phase of a larger study that sought to improve retention in prevention of vertical transmission care through appreciative inquiry (AI) and describes the experiences of expectant mothers who accepted HIV counselling and testing in the prevention of vertical transmission programme in a district hospital in Ghana. The other phases of the study will be published as other articles.

Methods

Parent study

A mixed-method sequential explanatory study was conducted from 2015 to 2018. The two-staged study encompassed a retrospective cohort study and an AI which was further conducted in four phases: Initiate, Inquire, Imagine and Innovate. The scope of this article is kerbed to the inquire phase of the AI process that sought to explore the experiences of the women in the prevention of vertical transmission programme. The AI process of inquiry is participative and inductive in nature and enables participants to share their experiences through storytelling. This method of inquiry was suitable for the study as it offered the women the opportunity to engage in a participatory process that allowed them to identify and amplify the aspects of their experiences and the prevention of vertical transmission programme that is life-giving to foster change. The full study design is described in the methods available elsewhere.⁷

Study design and participants

A qualitative explorative descriptive study was conducted to explore the experiences of expectant mothers who tested for HIV in the prevention of vertical transmission programme in a Ghanaian

district hospital. Participants were recruited based on the findings of the first phase of the study that sought to describe retention in the prevention of vertical transmission programme.

Approximately 1252 pregnant women were booked at the antenatal clinic in 2015. Of this number, 43 women tested positive throughout the prevention of vertical transmission cascade while only 29 women remained in the programme at postnatal and presented their infants for the EID at 6 weeks at the integrated prevention of vertical transmission and CWC. Using purposive sampling, 12 out of the 29 expectant mothers were recruited. This was because data saturation was achieved by the 12th interview. This may have been so because the sample used was homogeneous as the participants were selected according to a common criterion and the goal of the study was to describe a shared perception and behaviour relatively common to this cohort.⁸

Study setting

The study was sited at the antenatal clinic at a district hospital in the Sekondi-Takoradi Metropolis, Western Region of Ghana. It is a secondary referral receiving clients from four sub-district health facilities. The population served by the hospital has similar characteristics as the general population which is mostly youthful, economically active and literate.⁹ The facility also operates a walk-in policy for accessing health services. The focused antenatal approach is adopted in this setting, thus, following the initial registration at the antenatal clinic (ANC), follow-up visits are scheduled by appointments to the same health provider during the pregnancy. The district facility provided the full complement of the prevention of vertical transmission interventions, including counselling, testing and ART treatment (option B+) within the MNCH services, but sent exposed infants' DBS for PCR testing to the regional reference laboratory for analysis. In addition, education on retention and adherence counselling support services are provided to improve retention in care.

Data collection

Individual conversations were held with 12 women infected with HIV using the generative conversation technique,¹⁰ which uses storytelling to elicit information about the mothers' experiences. The conversations were conducted in

Fante (a native Ghanaian language), or English at the preference of the mothers, and lasted between 30 and 45 min. These were audio-recorded to enable the researcher enhance accuracy.¹¹

Data management and analysis

Analysis was conducted manually guided by Colaizzi's method.¹² This is a rigorous method of thematic analysis that allows for interpreting qualitative data. This method was chosen because it did not only allow for describing the data but further allowed for making meaning of the mothers' experiences. The analysis involved seven steps that began with the researcher immersing in the mothers' conversations by listening to the tapes repeatedly and reading the transcripts. Transcripts in Fante were translated into English and later back translation was conducted. Following this, statements that were noteworthy were identified and extracted from the dataset and imputed in a thematic analysis tracking map. Meanings were then generated from the statements. Thereafter, the formulated meanings were sorted into categories. Finally, clusters of the categories that reflected particular trends of thought were merged to form sub-themes and the themes. To ensure trustworthiness of study, the constructs proposed by Lincoln *et al.*¹³ were used as standard.

Ethical approval

The study was approved by the University of Cape Town Human Research Ethics Committee (HREC 917/2015) and Ghana Health Service Ethics Review Board (GHS-ERC011/05/16).

The study was also guided by the ethical principles of research proposed by Helsinki Declaration of Scientific Research.¹⁴ Pseudonyms were chosen by the participants to ensure confidentiality and anonymity. Participants gave informed consent both in writing and orally. Participants also signed informed consent regarding publishing their data.

Results

Sociodemographic characteristics of participants

Twelve women participated in the Inquire phase of the AI process. The youngest of the women was 18 years old while the oldest was 38. Half of

Table 1. Sociodemographic characteristics of the participants.

Pseudonym	Age	Parity	Marital status	Education	Employment	Disclosure status
Jane	32	2	Single	None	Trader	Not disclosed
Mary	34	3	Divorced	Primary	Trader	Not disclosed
Rejoice	27	2	Married	Vocational	Caterer	Not disclosed
Vera	18	1	Single	Secondary	Unemployed	Disclosed
Irene	35	1	Married	Secondary	Seamstress	Disclosed
Felicia	25	2	Married	Tertiary	Student	Disclosed
Lydia	38	4	Married	Primary	Trader	Disclosed
Blessing	20	1	Single	Secondary	Student	Disclosed
Comfort	27	2	Married	Vocational	Caterer	Disclosed
Grace	26	1	Married	Primary	Seamstress	Disclosed
Mercy	36	5	Widow	Primary	Trader	Not disclosed
Esther	33	4	Single	None	Trader	Disclosed

the participants (6/12) were married women. An equal proportion of the women (6/12) had no/primary education, and secondary education or higher. With the exception of three women (one unemployed and two students), others (9/12) were self-employed. Eight of the mothers had disclosed their HIV status to either their husbands or to an immediate family member. The sociodemographic characteristics of the mothers are presented in Table 1.

Emergent themes and sub-themes

Three key themes emerged: *The Pre-test Counselling Experiences*; *The Test*; and *After Talk: Post-test Counselling*. A summary of the themes is presented in Figure 1.

Theme 1: the pre-test counselling experiences. The expectant mothers had varied experiences while being counselling for HIV testing. Three sub-themes emerged: *Getting information on HIV testing*; *Mothers attitudes during counselling*; and *Seeking and taking consent*.

Getting information on HIV testing. Apart from four participants who had earlier experience with antenatal HIV testing in previous pregnancies, all others had not anticipated testing for HIV at

booking and were therefore not prepared for testing. All the participants were offered HCT at antenatal. The HIV testing policy was made known to the pregnant women during the group health education sessions:

I was late that day [of booking]. So, I sat behind and listened to the nurse tell us we will be tested for HIV. Everybody was quiet ... Jane

Each of the mothers was also offered individualized HIV pretest counselling session when they met the midwives for their focused antenatal care sessions. Pretest counselling was offered to patients during every visit unless it was documented in the patients' folder that an HIV test had been done and results filed, whether positive or negative. For several of the mothers, their knowledge of HIV was explored by the midwives and accurate information on prevention of vertical transmission was shared:

She asked me my knowledge on HIV, and when I told her, she spent a long time talking about how the virus can move from the me [mother] to the baby ... Lydia

A few of the mothers cited their risk for HIV was also explored, as well as the possible reaction to a positive test.

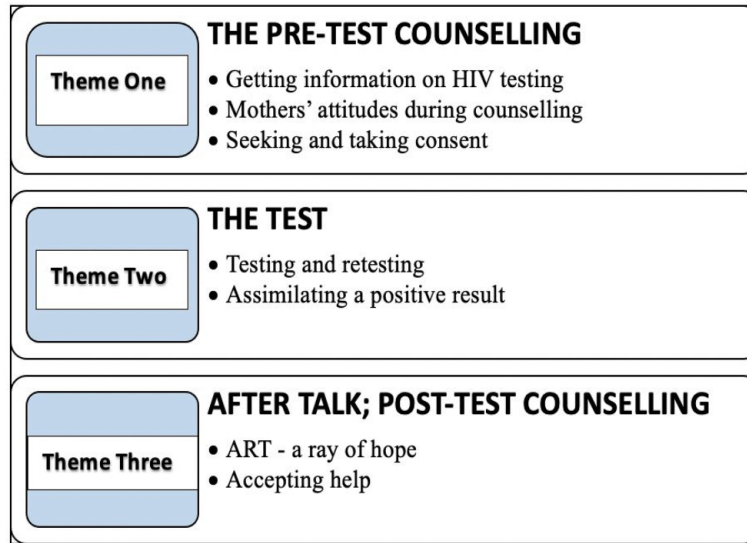


Figure 1. Summary of themes and sub-themes.

Mothers' attitudes during counselling. The attitudes of the participants largely depended on their prior experience with HIV testing in pregnancy. An HIV-negative result in a previous pregnancy and the perception of low risk to HIV were associated with indifference to the counselling session. This statement of a participant denotes this:

I had gone through this [HIV] test before with my first pregnancy. Honestly, I didn't even hear anything she [midwife] said during the counselling. Felicia

For those who had prior experience with HIV testing in a previous pregnancy, they accepted testing as a formality. Trivializing the outcome of the HIV testing eased the participants' anxiety and hesitation but also impacted on the expectation of the outcome and how they reacted following testing. For some of the mothers, the manner in which the pretest counselling was conducted ignited fear and unease towards HIV testing:

She asked me what if you test positive ... that was when I became scared to test. Blessing

Seeking and taking consent. The initial reaction of mothers with no previous HIV testing experience was hesitation. They were, however, informed the test was required during pregnancy and therefore the mothers accepted HIV testing because it was a policy that had to be complied with:

... she said, if you are pregnant, we test you for HIV, that is what we are instructed to do ... so I said ok. Blessing

For most of the participants, the individual counselling entailed being told HIV testing was essential for the sake of the child with little reference to the possible test result and how it would impact their lives:

She [midwife] insisted and said it [HIV testing] was required of all pregnant women so that they can protect the child. So, I said ok. Jane

Narratives from the mothers also revealed hurried pretest counselling sessions by the counsellors and limited time to reflect on or assimilate the information they received before the testing was conducted:

She [midwife] told me that I had to do the HIV test. So, she took me to the room in the corner and pricked my hand with the needle. Mary

Most of the participants felt the midwives were deliberately silent on the 'opt-out' component of the HCT approach. However, for those who were aware, some entertained the fear that opting-out of the testing would affect the care they will receive during their intrapartum period. This underscored the feeling that they had no choice in making a decision:

I was not sure if I refused to take the test, I will receive the best care ... so I agreed. Felicia

Theme 2: the test. All the participants took the HIV test in the antenatal consulting room. From the narratives, two sub-themes emerged: *Testing and retesting*; and *Assimilating a positive result*.

Testing and retesting. From the narratives, all the participants underwent two HIV tests: the initial test and the confirmatory test. Following an initial positive test result, all the women reported being offered and accepting to repeat the HIV test immediately after the initial positive test result:

After she said I was positive, I told her I wanted to do the test again, I didn't believe it ... but she told me that the brush they gave me to clean my tongue was the confirmation test. Comfort

A few of the participants, however, reported feeling ignored while they waited in nervous silence until the counsellor announced the result. The narratives also revealed varied experiences of receiving the test result. One participant chanced upon the result as the test kit lay on the table:

She placed it [test kit] in a way that I could see the results myself ... So when the two lines appeared on the test, I just knew I was finished. Mary

For most of the participants, however, the midwives broke the news of the test results to majority of them. This was done a few minutes after the test was concluded. Two were referred to another nurse who broke the news to them, while another read the results from the test strip.

For some of the participants, a positive confirmatory test represented a finality of their HIV-positive status. A few of the women expressed disbelief even following the confirmatory and visited other hospitals to retake the test:

I tested positive during my second ANC visit at hospital A, but I did not accept to be enrolled in care, I told them that I needed time to accept the diagnosis, but I went to hospital B the very next day and reported at ANC without informing them that I had visited another hospital, when the test was done and I was positive. Esther

Hospital shopping was therefore identified as a strategy employed by mothers to confirm their

HIV-positive status. Several of these women indicated reporting as new patients in the new facilities.

Assimilating a positive result. All the participants expressed varied emotional reactions to the positive HIV test. From the narratives, shock and denial were the most recurring initial reactions experienced:

No, I did not accept the news at that instance. I did not believe it. Irene

The reactions were usually attributed to their perceived risk of HIV which was aligned to their marital status or notion of faithfulness. Following the confirmatory test, however, most of the participants reported feelings of gloom, devastation and despair as the reality of their status set in:

Finding out I was HIV positive at the antenatal felt like the end of my life ... I felt dead ... Blessing

Although the participants finally accepted the positive HIV test result, imagining the impact of the result to their lives and that unborn child was paralysing and numbing:

I walked slowly from the office where the test was read to me, through the corridor where the other women were sitting, waiting to be tested ... my mind was blank ... I remember as I descended the stairs, the midwife run after me and held me by the waist and said ... Madam, we have to sit and talk. Esther

Theme 3: after-talk: post-test counselling. Post-test counselling was an integral part of the women's experience in the prevention of vertical transmission programme. Two sub-themes emerged following analysis: *ART – a ray of hope* and *Accepting help*.

ART – a ray of hope. All the participants stated that they received post-test counselling immediately after receiving the positive HIV test result. From the narratives, the availability of ART was the main topic of discussion:

I was counselled that the drugs were available to protect the child from getting infected. Irene

The drugs were presented as a lifeline to prevent vertical transmission of the virus. During counselling, emphasis on the well-being of the unborn

child as a reason to accept ART was found in the narratives:

She [midwife] told me that we had to plan for the child, how we can ensure that the child will not get the disease ... She [midwife] told me to agree to take the drugs to reduce the viral load so that the baby will not get infected ... Jane

The narratives also revealed the midwives/counsellors explained the infection as similar to other chronic diseases during the counselling session, thus enabling them to accept the chronicity of the illness and the need for lifelong management:

She [midwife] explained that it is a chronic disease like diabetes and others, so if I take care of myself well, I will live a normal life ... So, like the midwife said, if you don't think about it and you take your drugs like those other patients with chronic diseases, you will live long. Irene

Accepting help. All the women accepted being enrolled in the prevention of vertical transmission programme and to initiate ART. For three of the participants, treatment was initiated on the same day of testing, while others waited up-to 2 weeks:

She led me to the pharmacy and we talked to the man [pharmacist] there. Then after a lot of advice, they gave me drugs to last 2 weeks and asked me to come back before it finished.

For a participant who was a teenager, the counsellors requested disclosure of her status to a trusted person and to provide treatment supporter prior to the initiation of treatment:

She [nurse] counseled me and suggested that I disclose to my mother so that she will serve as my treatment supporter. So, when I got home, I thought hard about it and decided to tell my grandmother ... After the discussion, she ... helped us register. Vera

Discussion

The main findings of this study were, first, the policy requirement of offering HCT to all pregnant women who accessed antenatal services was implemented at the study setting. Second, pretest counselling was not optimum. Although disbelief was the initial reaction following a positive test, acceptance was reached following the confirmatory test.

Third, the post-test counselling was an opportunity for enrolling on treatment, counselling for disclosure and giving hope through education of preventing of vertical transmission.

In this study, HCT was offered to all pregnant women at antenatal booking as stipulated by the National Prevention of Vertical Transmission Policy.⁴ This finding is congruent with other studies in Vietnam¹⁵ and Ethiopia¹⁶ which reported that all pregnant women accessing ANC services received the offer of HCT. This is an essential step in achieving the UNAIDS targets of 90-90-90.¹⁷

Although pretest counselling aims to provide the women with information that will enable them make informed choices about HIV testing,¹⁸ this study found that for most of the participants, this was a formality and therefore they were not committed to the counselling session. Mitiku *et al.*¹⁹ also found that pregnant women in Ethiopia found the pretest counselling session to be limited and non-engaging. This could negatively affect the resolve of the women to test as well as accept a positive test result. To this effect, strategies should be implemented to strengthen the component of pretest counselling in the HCT service.

This study also found that several women were ignorant about their right to opt-out of HIV testing during pregnancy. Similar findings were reported in other African settings where health-care workers omitted to inform clients of the option to decline testing until such time when they were ready.^{20,21} This lack of knowledge resulted in lack of agency and deprived women of their rights to choice and ownership of HIV decision making.²² It is therefore essential that health managers and workers outline context-specific strategies as well as institute measure for monitoring to ensure that this core component of the HCT policy is implemented to empower the women as well as enable them own the outcome of the test result.

The attitudes of both the counsellor and the client were essential to the success of the counselling process. Although most of the midwives who provided the counselling service in the Prevention of vertical transmission programme ensured decorum and professionalism, a striking finding was that some midwives trivialized counselling in spite of the apparent gaps in mothers' knowledge

on HIV infection and prevention. Similarly, Kelly *et al.*²³ in their study reported midwives focused pretest counselling on the need of the HIV test but did not sensitize the pregnant women about the possibility for a positive result. Pretest counselling has reportedly been lacking in some prevention of vertical transmission services and even in instances where counselling was given prior to HIV testing, the approach was service-oriented rather than client-oriented.²⁴

The study also found that mothers visited several hospitals as new patients with the aim of confirming their HIV-positive status. Empirical studies to corroborate this finding were not found. However, this phenomenon reported by the expectant mothers was undetected by health workers because the Health Management Information Systems (HMIS) operated in the district at the time of the study were not linked between health facilities and thus repeated entries of records of patients who accessed care in different health facilities could not be detected. This has implications for surveillance and gives inflated prevalence and incidence rate as well as masks the gains of the country in achieving national and global targets. It is important therefore that the health system managers would implement measures to link the HMIS utilized in health facilities to ensure reliable data is achieved.

The study findings revealed that majority of the participants disclosed their status to their spouses. Similar studies in Ethiopia and Ivory Coast reported high incidences of HIV status disclosure, 86.5% and 96.7%, respectively, to male partners.^{25,26} The decision to disclose a positive HIV status remains mainly the woman's choice, but the policy in Ghana requires the health professional to counsel the woman on the need to disclose and the benefits during every meeting until the partner is informed and to also offer the needed assistance if so required by the client.²⁷ HIV status disclosure has positive implications for public health as it will be a catalyst for partners to also know their status, thereby increasing the chances of countries meeting the 95-95-95 agenda which targets 95% use combination approaches for HIV prevention, 95% of Persons living with HIV (PLHIV) know their status and 95% of those who know their status initiate treatment.²⁸ It will also contribute to safer sexual practices and prevent re-infection,²⁵ garner support

the woman in relation to the emotional, financial and social support as well as enhance the chances of adherence to ART treatment and strategies to reduce vertical transmission.^{26,29}

This study contributes new knowledge to the body of prevention of vertical transmission knowledge as it identified gaps in policy implementation which included health practitioners not informing expectant mothers of their right to opt-out of treatment during pretest counselling, thus depriving the women of their right to choose or informed consent.

The study also identified the phenomenon of hospital shopping adopted by pregnant women as a means to confirm their status.

The strength of the study is in the diversity of the sample based on their sociodemographic and clinical backgrounds and perspectives that provided rich data and capture core experiences.³⁰ Also, the Principal Investigator's position as a native speaker of the predominant language allowed for the permeation of language, meaning and culture during analysis. The researchers, however, acknowledge the study may be limited by possible recall bias as the participants were expected to share experiences that may have occurred more than 6 months. The possible impact of the limitation was, however, addressed using clarifications and feedback interviews as well as member checking to allow for the participants to report their experiences as close to the actual as possible.

Conclusion

Although HIV counselling and testing is offered in the facility, the implementation of the opt-out policy was either modified or omitted by the midwives to accomplish the policy expectations. Although this action might enhance uptake of the HIV counselling and testing, its impact on acceptability of the positive HIV results and subsequent uptake of services may be problematic. It is recommended that midwives providing HCT be trained periodically to enhance service delivery.

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Author contributions

Susanna Aba Abraham: Conceptualization, Formal analysis, Methodology, Project administration, Writing – original draft, Writing – review & editing.

Sheila E. Clow: Conceptualization, Supervision, Writing – review & editing.

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Supplemental material

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