

ORIGINAL ARTICLE

Experience and Perceptions of Self-disclosure Among People Living With HIV (PLHIV): A Qualitative Study

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ABSTRACT

Introduction: Self-disclosure is a complement to information about a person's health condition and is related to preventing HIV transmission. However, it is not uncommon for people living with HIV/AIDS to reveal their status because they are worried about stigma from society. This research aims to explore experience and perceptions of self-disclosure including social influence, social benefits, social risks, and reciprocity felt among PLHIV. **Materials and methods:** This research was a qualitative study with 5 main informants for PLHIV who revealed their status and 6 triangulated informants (partners, mothers, and health workers). The data analysis technique used Rapid and Rigorous Qualitative Data Analysis (RADaR). **Results:** There are efforts to reveal positive HIV status, including self-awareness of having carried out risky behavior, but there are obstacles to self-disclosure namely the risk of being stigmatized by society. The benefit of self-disclosure is getting support. The reciprocity of self-disclosure is the creation of an increasingly intimate relationship with family. **Conclusion:** Self-disclosure for PLHIV is related to considering the positive/negative influences that received by PLHIV, besides also considering the benefits for the lives of PLHIV, especially in undergoing medical therapy, risks in personal relationships, and responses from the interlocutor. **Recommendation:** There is a need for community-based interventions such as the involvement and empowerment of support groups, public figure and the use of social media to anticipated stigma and discrimination, and increase knowledge about HIV in the community.

Malaysian Journal of Medicine and Health Sciences (2024) 20(SUPP9): 120-127. doi:10.47836/mjmhs20.s9.19

Keywords: HIV/AIDS, Qualitative study, Self-disclosure, Social exchange theory, Social penetration theory

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INTRODUCTION

Self-disclosure is a complement to information about a person's health condition and is related to preventing HIV transmission (1). The link between self-disclosure and HIV/AIDS cases is that it is part of the basis for efforts to prevent secondary transmission, especially in people with active sexual behavior (2). Secondary transmission prevention is an action to reduce the impact of disease through early diagnosis and immediate treatment (3)(2). However, it is not uncommon for people living with HIV/AIDS (PLHIV) who do not want to disclose themselves because they are worried that it will cause stigma and discrimination from the surrounding community (4). The fear of receiving negative treatment is what causes PLHIV to not want to disclose themselves (5).

Indonesia is one of the countries in Asia with a fairly high

number of PLHIV, reaching 427,201 per year in 2020 (6). East Java as a province has the highest number of cases, namely 7,395 HIV and AIDS cases reaching 467 cases (6). Several districts/cities in East Java with high numbers of PLHIV and the city/regency with highest number of new cases were Sidoarjo (153), Tuban (49), Situbondo (41) and Blitar (29) (7). Blitar is included in the location with the lowest number of health service facilities when compared with 6 other districts/cities, consisting of 8 hospitals and 24 primary healthcares. Apart from that, HIV/AIDS consultation services are only provided in 3 healthcare facilities, namely Mardi Waluyo Regional Hospital, Srengat Regional Hospital, and Ngudi Waluyo Regional Hospital, so the researchers chose Blitar Regency as the place to carry out the research (8).

The high number of HIV cases is not commensurate with the willingness of PLHIV to self-disclose. Based on the results of research conducted by previous researchers, almost PLHIV did not want to tell other people about their HIV status, the reason being that disclosing themselves would not reduce anxiety and guilt over the illness that happened to them (9). In fact, self-disclosure

can create a sense of relief because someone can release the burdens in life (10).

Having HIV seropositive status is not just about health problem but also a social and psychosocial problem (11,12). If it is related to health, HIV is related to transmission and the treatment process (13), but if it is related to social and psychosocial issues, it is related to exclusion, stigma and discrimination as well as negative views from society (14). The effects of HIV infection are related to decreased self-acceptance and increased depression in PLHIV, which has implications for non-adherence with treatment, thereby reducing the expected optimal treatment results (15,16). Disclosure of HIV status will make it easier for PLHIV to gain an understanding of their disease, increase their self-confidence to carry out treatment, increase self-efficacy, and increase self-acceptance regarding their disease condition (17). At the end the implication is increasing adherence to ARV treatment therapy so that PLHIV are able to survive and be productive so they can improve their quality of life (17).

So the theory that discusses social problems is social exchange theory (SET), to explain the social influence and benefits that individuals receive from the act of disclosure (18). In self-disclosure, social influence is driven by positive and negative thoughts (19). The SET theory was developed into the Social Penetration Theory (SPT), this theory considers social risks and the reciprocity obtained (20). This research aims to (1) explore the social influences that make PLHIV want to reveal their HIV status, (2) explore the underlying social benefits, (3) explore the social risks experienced after self-disclosure and (4) explore the reciprocity felt by PLHIV after self-disclosure.

MATERIALS AND METHODS

Research design and location

This research used a qualitative research design to explore opinions that underlie self-disclosure among people living with HIV (PLHIV) in the Wlingi Health Center work area, Blitar Regency from August–October 2022.

Informants and How to Recruit Informants

The main informants in this research were 5 people with HIV/AIDS (PLHIV) who had revealed themselves as HIV/AIDS in 2020 and met the criteria determined by researchers, namely residing in the working area of the Wlingi Health Center, Blitar Regency. Data collection techniques use in-depth interviews, guided by 4 theme that want to explored (social influence, benefits. social, social risks, and reciprocity). This research used a source triangulation which aims to test the credibility or suitability of data. Triangulation of sources in this

research is the target of self-disclosure of PLHIV and health workers who handle HIV programs to find out the truth of the information.

Variables, Instruments, and Analysis

Research variables explore information related to the experience of disclosing PLHIV status based on several themes: (1) Social Influence is the experience of getting support from friends, family, relatives, or yourself in the form of real action. Social influence is divided into 2, namely positive influence in the form of encouraging support, appeals, attention, concern, affection, and assistance/assistance in accessing health services. Negative influence can take the form of terminating relationships for fear of contracting HIV. (2) Social Benefits explores the benefits perceived by PLHIV such as an increased sense of self-acceptance, the opportunity to be trusted to provide information about HIV prevention, being monitored or reminded to adhere to ARV therapy, reducing the burden so that you feel relieved and reducing stress. (3) Social Risks views on disclosing HIV status include denial of its existence, stigma and discrimination. (4) Inclinations toward reciprocity: the reciprocity that PLHIV will feel after self-disclosure is the creation of increasingly intimate relationships with mutual respect and respect, and increasing the sense of attention between PLHIV and the person they are talking to.

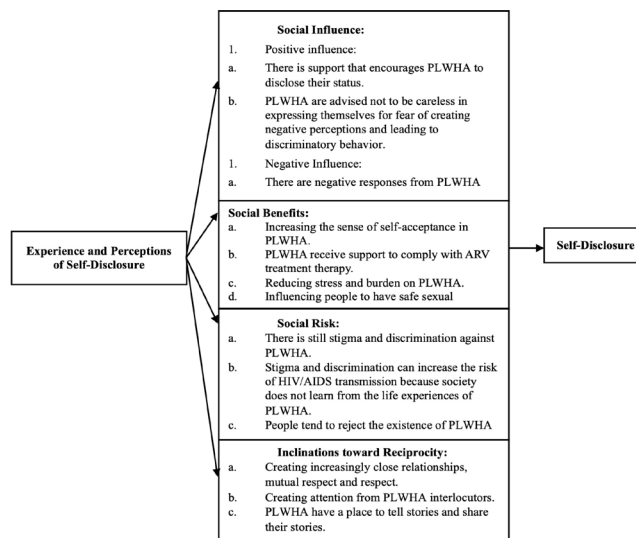


Figure 1: Conceptual Framework: Modification of social exchange theory (2010); social penetration theory (2010).

There are several factors that underlie PLWHA to self-disclose, namely social influence, social benefits, social risks, and reciprocity obtained between PLWHA and the target of self-disclosure. More consideration of the positive impact of self-disclosure can underlie and encourage PLWHA to self-disclose. Through the communication process of self-disclosure, PLWHA will receive support/motivation to comply with ARV treatment therapy so that they can improve their quality

of life and live their daily lives more productively.

This research is used interview guide tool that contains several open-ended questions (free response question) regarding the reasons for self-disclosure including social influence, social benefits, social risks, and inclinations toward reciprocity by PLHIV towards the target of self-disclosure. The information obtained was then analyzed using the Rapid and Rigorous Qualitative Data Analysis (RADaR) technique.

Ethical Considerations

This research was declared ethically appropriate on June 17 2022 with number: 247/FTMK/EP/VI/2022. Research informants also received souvenirs worth IDR 50,000.

RESULTS

Theme #1. Social Influence for PLHIV in Self-Disclosure Positive Influences that Encourage PLHIV to Make Self-Disclosure

Self-disclosure for PLHIV is driven by the need to receive support for compliance with treatment therapy, as in the following quote:

"Yes, I realized that I need support from other people, especially when I'm sick like this, so by telling stories about my condition, at least, burden on my mind can reducing and get advice for that, because I'm afraid my body will get worse, so my goal is to let someone help me to undergo treatment for this disease". (Female, 22y.o, married, transmission by sexual intercourse, 2 years has been PLHIV)

"Yes, people like us need advice from other people, especially if they are sick like this, so by telling about my condition, I can get advice to be faithfully to follow the treatment by the doctor recommendation." (Male, 24 y.o, married, transmission by sexual intercourse, 2 years has been PLHIV)

The other positive influence of self-disclosure is that it can reduce anxiety and create a sense of relief in PLHIV, as in the following quote:

"If someone pays attention, then I feel calm and I don't need to worry anymore because there are still people who really want to be my friends in situations like this." (Male, 28y.o, not married yet, transmission by needle drugs injection, 2 years has been PLHIV)

"Through the advice given, I can reduce my anxiety, so I feel a little relieved." (Male, 55 y.o, married, transmission by sexual intercourse, 2 years has been PLHIV)

The PLHIV's statement is supported by the triangulation informant's statement, namely that getting support and reducing the mental burden is the reason why PLHIV disclose their status, as in the following quote:

"They need support and advice to stay enthusiastic, especially to comply with medical therapy, but thank God, this patient's progress is good, because her weight has increased by 20 kg." (Health Worker, 45y.o, Female)

"Usually when they get bored of taking medicine or tired of their life then give them encouragement" (Wife, 23y.o, Female)

Negative Influences That Cause PLHIV to Refuse to Make Self-Disclosure

The results of the interview regarding the negative influences that cause PLHIV to refuse to express themselves are negative criticism from their interlocutors as in the following quote:

"My neighbor calling me bitch and didn't want to talk with me. so, from that response I thought, why am I telling, because the more I tell, the more people don't want to talk to me, so it's better to just keep it to yourself." (Female, 50 y.o, widowed, transmission by sexual intercourse, 2 years has been PLHIV)

"I no longer had any feelings of trust in other people. I thought it was useless if I told the story, so I worried myself because I had the experience of being shunned." (Male, 28y.o, not married yet, transmission by needle drugs injection, 2 years has been PLHIV)

Through interviews with triangulation informants, it was found that there were still negative views regarding PLHIV among the community due to a lack of knowledge about HIV disease, as in the following quote:

*"Poor knowledge about HIV/AIDS causes people to associate it with deviant behavior and then people tend to reject the existence of PLWHA."*menolak keberadaan ODHA." (Nephew, 22y.o, Female)

"Yes, afraid of spreading the infection, because my child often doesn't want to take part in many activities because he fear of become infected others" (Mother, 52y.o, Female)

Based on the results of interviews during the 2 years with PLHIV status, there has been no intention to disseminate information related to their condition to some people, one of the reasons is that PLHIV feels traumatized by the responses given by their interlocutors, as in the following quote:

"So actually, when people found out that I was working as sex worker, I immediately became the subject of gossip so since then I have been a quiet person. Like being did not care about what other people sad. So if you're sick like this, it's like you're not ready to talk about it. I'm afraid that I'll get unpleasant words and I'll feel hurt and it will add to the stress, which is difficult. It's what other people say that makes you hurt." (Female,

50 y.o, widowed, transmission by sexual intercourse, 2 years has been PLHIV)

"Actually, I not yet tell to my husband, because I still want to live with him" (Female, 22y.o, married, transmission by sexual intercourse, 2 years has been PLHIV)

This statement was supported by triangulation informants, that currently PLHIV do not want to tell other people about their condition, as in the following quote:

"Actually, he didn't want to tell me, but I was curious, why did he often go to the puskesmas and get medicine at the regional hospital, finally when my child was being checked, I went in to ask the health worker directly." (Nephew, 22y.o, Female)

"My child hasn't opened up much, I also feel sorry if I have to force him to tell the story." (Mother, 52y.o, Female)

Theme #2. Social benefits that encourage PLHIV to self-disclose

The benefit of self-disclosure for PLHIV is to obtain social support in the form of motivation, and advice to remain faithful in undergoing treatment therapy, such as the following quote:

"Because every sick person needs encouragement to increase adherence of taking medicine to get better quickly, that's why they need friends to talk and will get support, advice, and motivation to stay enthusiastic to take medication" (Female, 22y.o, married, transmission by sexual intercourse, 2 years has been PLHIV)

"The problem is that if a sick person is silent, it's impossible for other people to understand what is needed, so it's better to be open to getting help, for example, if you're in a low position or are in despair, bored of taking medicine, someone accompanies me, to increase my enthusiasm." (Male, 28y.o, not married yet, transmission by needle drugs injection, 2 years has been PLHIV)

"Yes, it's true, the proof is that I reminded you to continue getting regular treatment so you can recover quickly." (Male, 28y.o, not married yet, transmission by needle drugs injection, 2 years has been PLHIV)

Based on the statement made by the triangulation informant by disclosing one's condition, PLHIV will receive support/assistance as in the following quote:

"Yes, sick people can definitely get attention through stories so they can be more accepting of their own situation and still have the enthusiasm to recover by obeying the rules of medical therapy. Apart from that, I can also be ready whenever my child needs help and I

will try to help him." (Mother, 52y.o, Female)

Self-disclosure is also useful in making it easier for PLHIV to obtain ARV treatment because they get instructions on how to take ARV drugs, as in the following quote:

"If you are open, you will definitely get directions on how to take referrals, how to take medicine, and you can consult with health workers, so I won't be confused anymore." (Male, 55 y.o, married, transmission by sexual intercourse, 2 years has been PLHIV)

"Yes, there will definitely be a lot of help because in my opinion, being an HIV patient is a priority, the service is also good, you can share your complaints with the health workers and after that, you will be directed to get the medicine." (Male, 24 y.o, married, transmission by sexual intercourse, 2 years has been PLHIV)

Based on this statement, it is supported by health workers who hold the HIV program regarding treatment directions and patient consultations regarding the condition of PLWHA as in the following quote:

"We provide instructions on how to take ARV drugs. If the drugs are not yet available, we give a referral letter to the patient once every three months, this letter can be used as a condition for taking the drugs at the hospital." (Health Worker, 45y.o, Female)

PLHIV also receive social support after self-disclosure about daily life, such as the following quote:

"The advice I received not only about medication but also about adequate rest, eating fruit and vegetables" (Female, 22y.o, married, transmission by sexual intercourse, 2 years has been PLHIV)

Apart from the statement above, the benefits of self disclose are channeling stress and seeking support to survive, as in the following quote:

"By disclosing my condition, I can get the support that can encourage me to remain enthusiastic in living life and motivated to remain enthusiastic in following treatment therapy." (Male, 28y.o, not married yet, transmission by needle drugs injection, 2 years has been PLHIV)

"Yes, sick people need advice from other people, so by telling stories about my condition, I can at least channel my burden and get advice to follow faithfully the treatment." (Male, 24 y.o, married, transmission by sexual intercourse, 2 years has been PLHIV)

The opinion above is supported by the statement made by the triangulation informant, that the support given to PLHIV is related to motivation to remain enthusiastic in living life, as in the following quote:

"I try to convince my partner that the trials in life will

definitely have an end, this is one of the trials and it will definitely have a happy ending, so live it with enthusiasm.” (Husband, 26y.o, Male)

Theme #3. Social Risks of Self-Disclosure in PLHIV

Social risk is an obstacle felt by PLHIV when they want to disclose their condition, causing PLHIV to choose not to self-disclose. The results of interviews regarding examples of social risks from PLWHA’s interlocutors after self-disclosure are that there is still a stigma among PLHIV, including being considered low, as in the following quote:

“I was once criticized by my friend. There was a friend who said something like this, Salahe Sopo Ndugal Eram (it’s the fault of whoever is really naughty) that’s why I got HIV so I repent a lot, so I’m like a complete stranger, when I meet my friend.” (Male, 28y.o, not married yet, transmission by needle drugs injection, 2 years has been PLHIV)

The results of interviews conducted by researchers with 5 PLHIV patients in the Wlingi Health Center work area stated that the social risk felt by PLHIV when they wanted to reveal themselves was the rejection of the existence of PLHIV, as in the following quote:

“Yes, what is certain is that now there seems to be a distance between me and other people, perhaps you could say they are reluctant to contact me because they are afraid of being infected, which is what made me choose to lock myself up at home.” (Female, 50 y.o, widowed, transmission by sexual intercourse, 2 years has been PLHIV)

“It’s true, you’re afraid of being rejected, because sometimes when you get sick like this, it’s thought to be the result of deviant behavior, you’re afraid that people will end up saying bad things.” (Male, 24 y.o, married, transmission by sexual intercourse, 2 years has been PLHIV)

Rejection causes PLHIV to choose to close themselves off because they are not ready to be abandoned, as in the following quote:

“At that time my fiancé didn’t want to marry me and didn’t want to meet me, he was afraid of being infected. I’m desperate. Finally I chose to remain silent and cry alone in my room. So, I am afraid of being scolded, afraid that my story will be spread widely, and afraid that the person I love most (my partner) will leave me again.” (Female, 22y.o, married, transmission by sexual intercourse, 2 years has been PLHIV)

“Yes, I feel like it’s a mixture of doubt and worry because it could be a reason to separate.” (Male, 55 y.o, married, transmission by sexual intercourse, 2 years has been PLHIV)

The triangulation informant said that the obstacle to disclosing one’s condition was due to the fear of being rejected by society, as in the following quote:

“It could be that he feels uncomfortable because he is afraid that his existence will be rejected.” (Wife, 50y.o, Female)

“Did not ready to receive a response from others, so he usually think that if telling the truth, he will be rejected and it will be linked to deviant behavior.” (Wife, 45y.o, Female)

Theme #4. Reciprocity of Self-Disclosure Actions of Self-Disclosure

Responses from PLWHA’s interlocutors after disclosing their condition.

The results of the interview were the responses/attitudes of PLHIV interlocutors when listening to and responding to stories about PLWHA’s condition. PLHIV said that through self-disclosure they could get a positive response in the form of social support for adherence to ARV treatment therapy, as in the following quote:

“If it comes from my mother, you will definitely listen to all my stories, sometimes you will cry as if you feel sorry for me, but every time you tell the story, you have to stay enthusiastic, just follow the doctor’s advice, you will definitely recover like that.” (Male, 28y.o, not married yet, transmission by needle drugs injection, 2 years has been PLHIV)

“Yes, usually we listen to the story, because I complain a lot when the response is, always remind me that whatever the current situation is, it is always accepted, the important thing is to pray and try to take medication regularly, get enough rest, and eat regularly.” (Male, 24 y.o, married, transmission by sexual intercourse, 2 years has been PLHIV)

The results of the interview regarding the reciprocity of the act of self-disclosure, namely that PLHIV received care assistance, PLHIV said that it was their partner who helped provide care, one form of which was reminding them to take medication regularly, as in the following quote:

“In the past, my child used to help me get medicine, drink, and prepare my food, but now my child works in Malang, so I’m alone at home and I can’t take care of it myself, but sometimes my sister comes here to deliver vegetables, fruit, etc. rice, then go home.” (Female, 50 y.o, widowed, transmission by sexual intercourse, 2 years has been PLHIV)

“My mother, has to remembering to take medicine.” (Male, 28y.o, not married yet, transmission by needle

drugs injection, 2 years has been PLHIV) Based on the interview results, the reason PLHIV made self-disclosure was because they realized that they had a background that was at risk of HIV transmission, so they chose to share their experiences so that did not happen and experienced by others, as in the following quote:

“Yes, now I also realize that I am not a good person. In the past, I even gave my virginity to my boyfriend. Yes, there I already felt that I was also damaged, so I made money through that, by serving those people. So, now I spread the impact of my past behavior to some people and I support other women who have behavior like we are” (Female, 22y.o, married, transmission by sexual intercourse, 2 years has been PLHIV)

DISCUSSION

Social influence is divided into two, namely positive and negative influences as follows: Positive influence, namely the presence of self-awareness which encourages PLHIV to self-disclose, one of which is because they need support, advice and motivation from other people in living their lives. Apart from that, it can reduce anxiety and create a sense of relief in PLHIV. Through self-observation, PLHIV will experience psychological improvement, and those who experienced feelings of disappointment will bounce back and feel better (21,22). The target of self-closing for PLHIV is based on the close relationship that has been established so that PLHIV can open up to people who are considered able to understand their situation and not disseminate the information conveyed (23,24).

The social benefits of expressing themselves are that PLHIV gain social support and motivation to remain enthusiastic in living their lives (25,26). In this study, PLHIV stated that through their determination to tell other people about their condition, they could obtain social support, motivation/advice in undergoing ARV treatment therapy. Social support influences ARV treatment adherence among PLHIV because there are people who pay attention to and always improve PLHIV (14). This statement is in line with previous research that social support can help increase PLWHA's adherence in undergoing treatment therapy. When undergoing treatment therapy, of course PLHIV need attention from other people so that they feel comfortable and not burdened (25).

The social risk of revealing themselves to PLHIV is stigma and discrimination against HIV disease, for example, there is different treatment for PLHIV (27). Stigma is the negative view of other people towards PLHIV, for example the perception that they are doing something unnatural (27,28). One form of example is the opinion that HIV is seen as a cursed disease due to violating norms and religion, including having sexual relations with unmarried couples so that their existence

tends to be ostracized and rejected (discrimination occurs) (28,29). PLHIV expressed hesitation and lack of confidence in telling about their condition, because they were afraid of creating a distance between PLHIV and the target of spreading it because they thought they were afraid of contracting HIV by PLHIV, so PLHIV chose to close themselves off. The impact that occurs is the higher risk of HIV transmission because the public does not receive information regarding how to transmit HIV or preventive measures for HIV disease (30,31). Basically, stigma results in acts of discrimination, namely different forms of treatment towards PLHIV (31).

In this research, public stigma is a low and contemptuous view of PLHIV, so PLHIV are afraid that their existence will be rejected and abandoned. Facing this, PLHIV choose to close themselves off. PLWHA's refusal to self-disclose can accelerate the decline in body condition because they do not receive social support (32). Reciprocal self-delivery is the response given by the target/interlocutor that PLHIV expect. The act of reciprocal self-disclosure of PLHIV is a form of expression/response obtained after other people understand the condition of PLHIV (33). In this research, the reciprocity of self-disclosure is that PLHIV receive attention/care and can develop closer and more intimate relationships.

This research found that self-disclosure for PLHIV was only carried out in the inner circle such as family and the middle circle, namely people who were not too close but had an interest in disclosing their status in order to get the services and support they needed, such as counselors and health workers (35). However, there are no guidelines for disclosing the status of health services while the program is only limited to case finding and treatment recommendations. The government needs to pay attention to efforts to widely accept society so that disclosure of status becomes commonplace because it is closely related to the mental health of PLHIV and has implications for treatment compliance (26,35,36).

CONCLUSION

The positive social influence that makes PLHIV want to reveal their HIV status are getting motivation, reducing psychosocial distress, and creating a sense of relief. Meanwhile, the negative social influence are that PLHIV felt doubtful and lack self-confidence because they are afraid of being criticized and accused of having sex with someone than their partner. The social benefits of self-disclosure for PLWHA are getting support, advice and encouragement, especially when undergoing ARV treatment therapy. The social risk when PLHIV did self-disclosure are rejection of their existence and abandonment by others who is the target of self-disclosure. The reciprocity felt by PLHIV is other people's concern for PLHIV, such as reminding them to take medicine, eat more fruits, get enough rest and eat regularly. Meanwhile, the reciprocity for community is

they can increase their insight about HIV transmission. There is a need for community-based interventions such as the involvement and empowerment of support groups, public figure and the use of social media to reduce several barriers to PLHIV such as anticipated stigma and discrimination, and increase knowledge about HIV in the community.

ACKNOWLEDGEMENT

This work is supported by Publication Grants from Yayasan Bhakti Wiyata and We would like to thank the health workers who accompanied us during the research.

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