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Original Research Paper

Perspectives of people with HIV/AIDS on psychosocial disorders on motivation and quality of Life

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Abstract

The cause of death of people with HIV/AIDS (ODHA) is not only caused by immunodeficiency factors but also caused by the influence of stigma or social discrimination received, resulting in psychosocial disorders on motivation and quality of life. This study aims to determine the perspective of PLHIV on psychosocial disorders due to discrimination and stigma received and its impact. This research is a qualitative research with a field research design. Data collection using Focus Group Discussion and in-depth interviews involving 18 informants at Yayasan Pelangi Maluku. The impact of psychosocial disorders is experienced as a decrease in the quality and motivation of life. Decreased quality of life was reported by informants, including poor social relationships, problems accepting HIV status, and anger of PLHIV towards themselves. The decrease in motivation to live with PLHIV is reflected in the unwillingness to seek treatment, suicidal ideation, and the desire to transmit HIV. This study showed the existence of psychosocial disorders with a large impact on the motivation and quality of life of PLHIV. This shows the importance of psychosocial assistance to PLHIV through continuous education for families and communities to reduce stigma and discrimination and its impact on PLHIV.

Keywords: discrimination; HIV/AIDS; life motivation; psychosicial disorders; quality of life

1. Introduction

The prevention and management of HIV/AIDS is a significant health challenge affecting the global population (Klionsky et al., 2021). Developed countries have made progress in dealing with this epidemic. However, some developing countries with limited resources continue to grapple with the impact of HIV/AIDS, which has claimed many lives (SeyedAlinaghi et al., 2021). The number of HIV/AIDS cases in 2019 globally reached 36.85 million cases, with cases of death and disability-adjusted life years (DALYs) of 863.84 thousand and 47.63 million respectively (Tian et al., 2023). Indonesia is a country in Southeast Asia with the highest prevalence of mortality due to HIV/AIDS reaching around 39,000 people (UNAIDS, 2019).

People with HIV/AIDS (ODHA) are facing complex physical and psychosocial problems. Psychosocial disorders are any changes in a person's life that are social or psychological in nature with a reciprocal influence, can have great potential for the incidence of mental disorders or physical health problems, and can have an impact on the social environment (Krisdayanti & Hutasoit, 2019). Psychosocial disorders faced by HIV/AIDS patients include feeling worried about their physical condition related to an unpredictable decline in the immune system and withdrawing from associations because of feelings of shame (Amalia et al., 2018). Others include loss of enthusiasm for life due to limited socialization with others or isolation from society, lifestyle changes, financial problems due to having to seek treatment every time, prolonged grief due to frustration with their situation after infection, feeling guilty, depression, and fear of death (Kalembo et al., 2019). Research by Mukarromah and Azinar (2021) proves that HIV/AIDS patients have increased motivation to live, a desire to recover, and adherence to taking medication if there is motivation from within the patient himself, moral support from family, and people around him. On the other hand, Armiyati et al. (2015) found that after being diagnosed with HIV, patients tend to experience psychosocial problems such as shame, marginalization, and a lack of enthusiasm for life as a result of judgment from people who do not understand PLHIV.

Both stigma and discrimination that develop in the community or in the patient's family or friends about HIV/AIDS can cause psychosocial disorders in HIV/AIDS patients (WHO, 2017). Stigma is an obstacle to the potential psychological support of HIV patients in developing countries (Kalembo et al., 2019). Stigma among PLHIV is quite high and causes some PLHIV to feel depressed, ashamed, humiliated, hopeless, isolated, have reduced social support, and be reluctant to access health services (B. T. Chan & Tsai, 2016; Swan, 2016; Ziersch et al., 2021). Stigma and mental health have a complex relationship (Fekete et al., 2018; Yi et al., 2015). Stigma and discrimination against PLHIV are associated with poor mental health outcomes, including post-traumatic stress, low self-esteem, anxiety, depression, suicidal ideation, and attempts (Chambers et al., 2015; Yi et al., 2015). Stigma and discrimination form a toxic social environment that has the potential to interfere with mental health (Mendonca et al., 2023), which has an impact on their quality of life (Ebrahimi Kalan et al., 2019; Nobre et al., 2018; Rasoolinajad et al., 2018; Rueda et al., 2016).

From the literature review during the research, it turns out that there is still little literature specifically discussing psychosocial disorders related to the motivation and quality of life of PLHIV in Indonesia, especially in Ambon City. It turns out that there is still little literature that specifically discusses psychosocial disorders related to the motivation and quality of life of PLHIV in Indonesia, especially in Ambon City. Research on the problem of psychosocial disorders with a qualitative approach in PLHIV patients in Ambon City needs to be carried out, considering that within one year (2021-2022), there has been a significant increase in HIV/AIDS cases in Ambon City to reach 133% from 116 cases to 271 cases (Siwalimanews, 2023). This study aims to explore the perspective of PLHIV related to psychosocial disorders and their impact on their motivation and quality of life. The results of this study are expected to be taken into consideration in developing strategies to increase the motivation and quality of life of PLHIV, as well as an assessment of whether special services are needed or related to psychosocial disorders in HIV/AIDS patients.

2. Research Methods

2.1. Research Design

This research is qualitative research with a field research design. Qualitative research is conducted to understand certain individuals, groups, or institutions in depth (Moleong, 2010).

2.2. Research Sites

The research was conducted at Yayasan Pelangi Maluku. This foundation has been active in the health sector, especially HIV/AIDS, since 2000 and has collaborated with most hospitals, clinics, and puskesmas in Maluku Province so that every patient who gets a positive HIV/AIDS test result can be directly recorded for advocacy, guidance, and/or assistance.

2.3. Informant

The informants in this study consisted of the main informants and supporting informants. The main informant is an HIV/AIDS patient who receives guidance and assistance from the Pelangi Maluku Foundation. In contrast, the supporting informant is a companion or patient coach at the

Pelangi Maluku Foundation. Purposive sampling is used to select informants. Purposive sampling is a technique with certain considerations (Sugiyono, 2015). The main informants were taken based on inclusion criteria: PLHIV, whom Yayasan Pelangi Maluku fostered, were willing to be respondents and could communicate well. This study involved 18 people as main informants and six as accompanying informants.

2.4.Data collection and analysis

In this study, a companion from the Pelangi Maluku Foundation became a mediator who connected researchers with the main informant. The escort asks for the willingness of the main informant to participate in the research. Informants who agree to participate must sign written consent. The data in this study was obtained through focus group discussions (FGD) and in-depth interviews (WM). The interaction in FGD is expected to provide varied answers within the group. Researchers formed two FGD groups for PLHIV based on sex, each comprising six people, as shown in Table 1. FGDs were conducted once per group of primary informants for approximately two hours per group.

Table 1. Data Collection Methods

Types of Informants	Data Collection Method	Number of informants
Male Patient	FGD In-Depth Interviews	1 group (6 persons) Three persons
Female Patient	FGD In-Depth Interviews	1 group (6 person) Three persons
Companion	In-Depth Interviews	Six person

An in-depth interview (WM) was conducted after the FGD was completed. In-depth interviews aim to explore information about the psychosocial disorders of PLHIV patients based on the perspectives of the main informants and supporting informants. The informants for the interview were the same as the informants in the FGD, totaling 12 informants (six main informants and six supporting informants). Open and unstructured interviews were used in this study, where researchers are free to start conversations without being fixated on interview guidelines that have been made so that they can get deeper information from informants (Sugiyono, 2015). Interviews were conducted face-to-face, with a duration of approximately one hour per informant. The researcher has asked the informant for permission to record all WM and FGD activities with a voice recorder.

2.5.Data Analytics and Trustworthiness

Data analysis is conducted using the content analysis method of induction, concluding specific things to general things (Moleong, 2010). In the first stage, data review is carried out, followed by data reduction and summarizing, data preparation, data categorization, and data interpretation. The validity of the data can be improved by using the triangulation method (Moleong, 2010). Researchers used the triangulation of sources and methods to increase the validity of the data in this study.

2.6.Research Ethics

This research has been approved by the Ethics Commission of the Faculty of Medicine, Pattimura University, with No. 024/FK-KOM. ETIK/II/2020. Before the data collection, informants had been briefed on the research and their rights, including the right to resign at any time. After the informed consent process is carried out and the informant approves, the informant signs a written consent sheet. Finally, to maintain anonymity, the respondent's identity is kept secret.

3. Result and Discussion

3.1.Results

The results of this study show three main findings related to the perspective of people with HIV/AIDS on psychosocial disorders on motivation and quality of life, namely the impact of psychosocial disorders of PLHIV due to discrimination on quality of life, the impact of psychosocial disorders of PLHIV due to discrimination on life motivation, and efforts to minimize psychosocial disorders due to discrimination in PLHIV.

3.1.1. Impact of Psychosocial Disorders of PLHIV Due to Discrimination on Quality of Life

3.1.1.1.Problems of accepting HIV status

Most informants deny HIV status and tend to blame themselves.

> "I do not want to accept the status of an HIV-infected person. Honestly (taking deep breaths and exhaling spontaneously), the first thing I felt must have been the thought of being 'dead already'. Oath! That is what I had in mind first when riding the bike. God, I want an accident now. I want to die today, this afternoon when I go to take this status of mine'. I knew over the phone that I was positive. Because as usual consultation by telephone. So when I got the call, I messed up my mind when I found out I was HIV positive." **(Informant 3, WM PLHIV Male)**
>
> "At the first moment of denying [HIV status]. Like I blame people and blame myself, it is huge,..'agh why should I be like this? Why should I get this disease?' surely that is it, the resistance from within is there, it's impossible. Still, I personally do not want it. **(Informant 6, FGD PLHIV Male)**

3.1.1.2.Poor Social Relations

a. Social Isolation

Informants avoid stigma and hide their illnesses by restricting and disconnecting their social relationships and distancing themselves from society.

> "The reaction [at the first time receiving the status] was silence and not wanting to talk to anyone at all." **(Informant 5, WM Companion of PLHIV)**
>
> "Some of them immediately shut themselves up when they first found out they were infected, some were crying hysterically. That's how they reacted. Anyway, they are afraid and do not want to meet anyone, as someone influenced them from their social environment. For example, they initially hang out with anyone, but when they know their status as people with HIV, they begin to isolate themselves. They are indeed friends, but no longer as free as before. They seem to still close themselves. I also often ask them why? They say, 'My brother needs time', I see." **(Informant 4, WM Companion PLHIV)**
>
> "It also depends on each person whether they really have the courage to open up about (HIV status). But if they do not want to open up, keep it to themselves instead of hearing the sneers of the community." **(Informant 1, WM PLHIV Female)**

b. Rejection and Discrimination from the Family

Some informants said they were reluctant to share their HIV status with their families due to concerns about confidentiality, rejection, and discrimination from families.

> "I myself have so far chosen silence, and not a single one of my family members knows about it. Why? Usually, the most delicious and most difficult circumstances arise from the family. The

> family can love us, but it can also bring the family down. From what was originally a motivation, it developed into story material, which was then spread to other family members. This is what eventually makes us ashamed of ourselves. For me, someone else should know this than my own family. It is the common view that it is usually family, so it is better to chat with others. Yes, that is better." **(Informant 1, FGD PLHIV male)**
>
> “... There is a term for "better people others know than their own family members". These people can appreciate more than their own family members." Why do I say that? Because of the good and bad qualities of a person, it arises from the family. The worst thing is that it is the family that creates discrimination against PLHIV. That is why I prefer to chat with other people. Their thinking contributions are sometimes clearer than those of family. Because if the family understands it, they will definitely separate cutlery such as plates, spoons, and glasses. They would also separate towels, including buckets and utensils we wore. We were separated from family members and other relatives so as not to be infected. Instead of being expelled later, or told to board, or any other possibility that I do not know about" **(Informant 2, WM PLHIV male)**

Supporting informants revealed that some PLHIV experience rejection and discrimination from their families, which causes them to experience severe stress and depression.

> “This patient, however, would have had severe depression and was very disturbed psychosocially and psychologically. His condition as an HIV-positive person has made him depressed and stressed, especially to the point of having to take medication for life. Moreover, his status as an HIV sufferer was disseminated to the surrounding community. That is why negative, unsupportive responses and attitudes from family and society make patients eventually experience major depression." **(Informant 1, WM Companion PLHIV)**
>
> “The patient is an orphan, and none of his family wants to accept him in such circumstances. His family distanced him when he found out he was HIV positive. They all disappeared." **(Informant 1, WM Companion of PLHIV)**
>
> “There are one or two patients who have very severe psychological disorders. This casein is not only because of his status as an HIV-positive person but also because of his home life. His in-laws separated him from his family members, namely his children. His gaze went blank. Such patients are difficult to accompany." **(Informant 6, WM Companion PLHIV)**

c. Rejection and Discrimination from Society

Informants revealed that they also received rejection and discrimination from community members. They received ridicule, slander, expulsion, and death threats.

> “For me, who lives in a community environment, we cannot just be open and straightforward. Neighbors (attitudes and characters) are different from one another. Once they heard about this [someone with HIV status], they would immediately sneer. They would mock us when we passed in front of them, muttering... while his fingers pointed at the patient with many mockings. They cannot accept it and try to make bullying happen wherever they gather. **(Informant 1, WM PLHIV female)**
>
> “If the people kick me out of the village, it means that I am being slandered. They probably would not hesitate to kill me under these circumstances. Eviction can come from the burning of

> the house. Haa??? Like this. In the village, there are six people with HIV status. Five of them fell, and all died, and I was left alive. However, this matter he considered strange. How could others die I was still alive. There were assumptions among them that I had a certain knowledge." **(Informant 4, FGD PLHIV Male)**

The discrimination experienced by PLHIV also has an impact on their treatment. Informant supporting 6, as a companion of PLHIV, revealed that discrimination makes PLHIV ashamed to take drugs.

> "There are so many [HIV-positive] people who feel embarrassed when they say they want to take medicine, because of what? They are afraid of facing discriminatory treatment." **(Informant 6, WM Companion PLHIV)**

3.1.2. Impact of Psychosocial Disorders of PLHIV Due to Discrimination on Life Motivation

Most informants in the study said that when they were told their status as HIV-positive, the first thing they thought about was not wanting treatment and wanting to end their lives.

> “The first of all, I don't want to do treatment. Could it be that I'd rather just die, than have to go for treatment." (**Informant 6, FGD PLHIV Male**)

> “It feels like hanging yourself in the room. People say depression is starting to rise. Thinking about taking medicine finally died, not taking medicine will die.” (**Informant 3, WM PLHIV Male**)

The same thing was conveyed by supporting informants.

> “They do what they want to do. The most severe thing is to commit suicide. Almost committed suicide, because of the depression I just mentioned. Once I had one client. He said, 'Sister I am very stressed, if I want to die I just want to die now.**" (Informant 1, WM Companion of PLHIV)**

Besides self-discrimination and suicidal ideation, PLHIV suffers from a desire to transmit HIV to others. This often arises in the minds of PLHIV.

> “... It must be like this. Ah, I've been infected with HIV, I can't possibly bear it myself. I have to pass it on to others. It was the first thought in the brain at that time." **(Informant 6, FGD PLHIV Male)**

> “There was actually an experience when I had assistance in the complex part of the house. also that he had a bad thought that immediately appeared: He wants to spread the virus that is in his body to him, and he has friends of his own."**(Informant 5, WM Companion of PLHIV)**

3.1.3. Efforts to Minimize Psychosocial Disorders Due to Discrimination Against PLHIV

The self-acceptance of patient in HIV status is one of the keys in dealing with psychosocial disorders in PLHIV, as expressed by supporting informants 1, 2, 5 as companions of PLHIV.

> “... so I always think that the social thinking of someone [PLHIV] should be straightened out [regarding status acceptance]. If there is no alignment, depressive disorders or severe stress, will appear at any time, either by causes from himself or people outside himself in the form of innuendos sneers. Therefore, self-acceptance of his status as an HIV person is very important." *(***Informant 1, WM Companion of PLHIV***)*

> “The point is, to overcome the psychosocial problems of PLHIV, the first thing to do is to convince PLHIV to accept their status as people with HIV." *(***Informant 2, WM Companion of PLHIV***)*
>
> “...it all [problems with their social environment] depends on those [PLHIV] who have problems with accepting their status. If they have no problems with receiving their status, automatically, in just a few months, their condition has recovered. So, to be able to minimize psychological disorders, they must first accept their status as PLHIV. After that, it only solves social problems such as discrimination. So first of all, they have to accept their status and solve their problems." ***(*Informant 5, WM Companion of PLHIV*)***

Peer companions are also felt to have a positive impact on PLHIV to overcome psychosocial disorders.

> “Their peers are actually to provide motivation, suggestions, and positive values. Similarly, employees of Yayasan Pelangi Maluku know me. It all gives positive values, which is useful for me." ***(*Informant 2, WM PLHIV Male*)***
>
> “Through this foundation, we [PLHIV] have courage. This foundation encourages us to have courage. First, people with HIV certainly do not dare to show their identity. That's the first one. Naturally, there is a companion from this foundation so that PLHIV feels they have many friends who support each other. With this, courage arises in PLHIV to be open in their social environment until they recover or are healthy, even though the virus remains." ***(*Informant 6, FGD PLHIV Male*)***

3.2.Discussion

Psychosocial disorders experienced by PLHIV due to discrimination have an impact on decreasing their quality of life. Deterioration in quality of life was reported by informants, including problems accepting HIV status and poor social relationships. We found that the problem of accepting HIV status in the form of rejection and feelings of anger toward oneself is a psychological disorder experienced by most people infected with HIV. HIV is a highly stigmatized disease in multiracial communities due to fear of moral judgment and social isolation (Ziersch et al., 2021). The status of HIV in Indonesian culture is still considered taboo, so negative stigma is still attached to HIV itself because HIV is almost always associated with deviant behavior, such as commercial sex workers, homosexuals, and drug users (Shaluhiyah et al., 2015). The existence of negative stigma in the social environment about HIV has an impact on the self-stigma of PLHIV (Chime et al., 2019; Turan et al., 2017). This can cause infected people to experience emotional and stressful reactions, leading to self-blame, status denial, social deviance, and reluctance to seek help or access health services, as well as hiding their status (Forouzan et al., 2013; Saki et al., 2015; Turan et al., 2017).

The impact of psychosocial disorders due to discrimination on the quality of life of PLHIV, in addition to affecting the acceptance of status, also has an impact on poor social relations. Poor social relations are evident from social isolation, rejection, and discrimination from family and society. When individuals are declared infected with HIV, most show changes in their attitudes and/or psychosocial characteristics, such as stress, depression, feeling alone, and other behavioral changes (Amalia et al., 2018; Girianto & Wiwik, 2017). This is also shown in the stages of psychological reactions of HIV patients to the environment, namely shock, self-isolation, limited opening status, looking for others who are fellow HIV positive, special status, caring behavior of others, and stages of self-acceptance (R. C. H. Chan et al., 2020; Rezaei et al., 2019).

The results of this study show that when first tested positive for HIV, key informants tend to withdraw from social and community associations, which leads to social isolation. They are even reluctant to disclose their HIV status to their families due to concerns about confidentiality, fear of rejection, and discrimination from families. This is also shown in the stages of psychological reactions of HIV patients to the environment, namely shock, self-isolation, limited opening status, looking for others who are fellow HIV positive, special status, caring behavior of others, and stages of self-acceptance (R. C. H. Chan et al., 2020; Rezaei et al., 2019).

The discrimination committed by families and communities in this study was due to a lack of knowledge and understanding about HIV. According to Fauk et al. (2021) several factors that trigger stigma and discrimination in PLHIV include ignorance about HIV, fear of HIV, and social and moral perspectives related to HIV. Forms of discrimination experienced by informants in this study include sneering, slander, expulsion, and death threats. Previous research has shown that there are many forms of discrimination from families faced by PLHIV, for example, when others refuse to share food or a room with them or when their personal belongings and utensils are kept separate from those of other family members and ostracized (Halli et al., 2017; Ruffell, 2017). In addition to discrimination from family, PLHIV is also at risk of facing stigma and discrimination from society (neighbors, friends, and coworkers) in the form of rejection, neglect, avoidance, ridicule, verbal abuse, insults, and harassment (Fauk et al., 2021; Ruffell, 2017).

The discrimination received by PLHIV will directly result in their psychological disorders. Most of them experience psychological disorders in the form of stress and/or depression (Amalia et al., 2018). This study showed similar results, where discrimination caused PLHIV to experience severe stress and depression and hindered treatment. Another study by Kalembo et al. (2019) also shows that discrimination in PLHIV greatly affects the progression of the disease and is one of the factors in psychosocial disorders that have a clinical impact. Decreased physical condition, high threat of death, coupled with discrimination or bad stigma addressed to PLHIV that causes their high psychological disorders that can cause a decrease in the quality of life of PLHIV (Girianto & Wiwik, 2017). Research conducted by Nasir et al. (2023) found the same thing about the poor quality of life of PLHIV with depression due to discrimination and/or bad stigma in the PLHIV environment.

In addition to a decrease in quality of life, psychosocial disorders due to discrimination among PLHIV patients can also cause a decrease in their motivation to live PLHIV. The decrease in motivation is reflected in the unwillingness to seek treatment, suicidal ideation, and the desire to transmit HIV. The informants do not want to seek treatment because they assume that whether they do or not, they will still die. Some previous research results show that emotional problems, fear of revealing HIV status, stigma and rejection from the community, and worry about side effects of treatment are the causes of PLHIV not taking treatment (Ahmed et al., 2018; Katz et al., 2015; Mey et al., 2017).

The psychological burden felt by HIV patients, both because of the symptoms of HIV disease itself and the social burden that will arise, causes anxiety, severe depression, and suicidal ideation (Rezaei et al., 2019). Tsai et al. (2022) found that the prevalence of suicidal ideation in PLHIV reached 22.3%, with suicide attempts and deaths due to suicide at 9.6% and 1.7%, respectively. Suicidal ideation in PLHIV is significantly associated with anxiety, depression, physical activity, and poor sleep quality (Dabaghzadeh et al., 2015). Stigma and discrimination indirectly trigger the desire of PLHIV to end their lives. The inability of PLHIV to manage stress and/or depression due to negative stigma and discrimination from the surrounding environment causes the desire of PLHIV to commit suicide (Amalia et al., 2018).

This study also found that the problem of accepting HIV status in the form of rejection of HIV status experienced by PLHIV greatly affects their social life. Self-acceptance of HIV status has a positive impact on PLHIV (Nasir et al., 2023). Accepting HIV status encourages a person to seek health care and is often accompanied by a sense of need and value for HIV medical care (Horter et al., 2017). Eliminating stigma and discrimination must also be done so that PLHIV is more accepted by families and communities (Dahlui et al., 2015) because living a carefree life in an environment that is willing to accept them is the expectation of PLHIV (Nasir et al., 2023). Increasing public awareness and knowledge, providing education to PLHIV, increasing self-efficacy, providing social and physical support, and advocating for the rights of PLHIV are strategies that can be done to combat stigma in PLHIV (Chambers et al., 2015; Dos Santos et al., 2014).

Providing support and motivation to PLHIV is also expected to help PLHIV accept HIV status, improve mental health, and increase access to health services. Peer support groups (PSG) can be a solution to solving the problem of depression in HIV patients because HIV patients tend not to report psychological problems to psychologists or doctors who treat them. That is why sometimes there is neglect of depressive symptoms, which can have an impact on treatment failure, which ends in death (Kalembo et al., 2019; Menon et al., 2015). Peer support groups are more effective in reducing the rates of depression in HIV patients than without PSG through the encouragement and emotional recovery provided for people living with HIV. (Menon et al., 2015; Simmons et al., 2023). Not only has PSG the potential to encourage and recover emotionally from HIV patients, but it is also able to influence the process of handling stigma or discrimination obtained by PLHIV and become the most effective means for disseminating information that is useful for accepting HIV status, following treatment, and how to overcome the side effects of treatment (Menon et al., 2015).

4. Conclusion

Based on the perspective of PLHIV, the effects of psychosocial disorders on life motivation begin with self-acceptance of HIV status and then have an impact on self-discrimination against the surrounding environment, suicidal ideation, and the desire to transmit HIV to others. In addition, discrimination carried out by families and the environment causes psychosocial disorders in PLHIV and affects their quality of life. These findings show the importance of psychosocial support from all parties, especially the government, through policies that can help PLHIV improve their motivation and quality of life. In addition, education related to HIV/AIDS for the community, especially families, needs to be carried out on an ongoing basis to combat stigma and discrimination against PLHIV in the community. Further research is expected to be carried out by focusing on other problems, both psychological and non-psychological, not only from the perspective of PLHIV but also from the perspective of the family and community environment.

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