Emotional responses, status disclosure, stigma, and hope among people living with HIV: a phenomenological study

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Abstract

HIV/AIDS cases continue to increase globally and nationally. In Indonesia, West Kalimantan has the highest HIV/AIDS incidence, especially in Pontianak City. This study employs a descriptive qualitative design with a phenomenological approach to explore the emotional experiences of individuals living with HIV (Person/People Living with HIV, PLHIV) within this demographic. A purposive sampling technique was used to select twelve participants, aged 18 to 60, who were active Community Peer Group Support members at Yayasan Pontianak Plus. Data were collected through in-depth interviews and observations. Thematic analysis, utilizing Colaizzi's method, identified four major themes: i) emotional responses to HIV confirmation, which include two subthemes: acceptance and denial; ii) disclosure status, which comprises two subthemes: undisclosed and disclosed; iii) stigma and perception, which include sources of stigma and forms of HIV stigma; and iv) hope for the future, consisting of hopes for themselves and hopes for others. This study enhances understanding of the complex emotional landscape of PLHIV and underscores the crucial role of social support in fostering resilience and hope.

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Introduction

Since the first case of HIV/AIDS was reported in 1981, there has been a yearly increase. The prevalence of HIV/AIDS among young people has increasingly become a focal point in Indonesia each year. Globally, in 2022, UNICEF recorded 1.65 million adolescents aged 10-19 years living with HIV. According to the Pediatric Association Report (2022), the age group of 15-19 years old, classified as adolescents, exhibits the highest prevalence of HIV infection, with approximately 741 adolescents affected.[1] According to UNICEF Indonesia, adolescents' knowledge of HIV/AIDS has increased but is still limited.[2] The distribution of HIV/AIDS in 2020 in West Kalimantan, especially Pontianak City, has ranked first with the highest number of cases, followed by Mempawah and Singkawang Regencies. Based on the report of the Infectious Disease Prevention and Control Section of the Health Service in West Kalimantan in 2022, the most significant percentage of HIV/AIDS cases occurred in the 25-49 age group (71.2%), followed by the 20-24 age group (17.7%), ≥50 years (5.3%), 15-19 years (4.5%), ≤4 years (1.1%), and 5-14 years (0.2%).[3]

AIDS comprises a series of diseases induced by HIV, which is transmissible and lethal. The virus harms the human immune system, leading to reduced immunity, particularly when T lymphocytes are affected, resulting in decreased CD4 cells that are crucial for combating infections. An individual infected with HIV experiences a compromised immune system, which significantly increases their vulnerability to serious diseases and may ultimately result in mortality.[4]

Since 2010, the global spread of HIV/AIDS among adolescents has decreased, but this decline is not significant when compared to the overall increase in cases. UNICEF stated that in 2020, adolescents contributed to 5% of all People Living with HIV (PLHIV), which is around 1.7 million people aged 10-24 years.[5]

Despite the global effort, gaps in youth knowledge about HIV/AIDS remain a critical public health challenge, especially in resource-limited settings.[6] The phenomenon of HIV/AIDS remains a significant global public health concern, affecting millions of individuals worldwide. Alongside its medical implications, HIV/AIDS presents complex emotional and social chal-

lenges for PLHIV. Emotional responsiveness, the ability to perceive, understand, and manage emotions effectively, is a critical factor that shapes the psychological and social experiences of PLHIV. Research indicates that emotional responsiveness influences how individuals cope with the stress of living with a chronic illness, particularly one as stigmatized as HIV.[7] Recognizing the importance of emotional responsiveness can lead to more empathetic care and support for people living with HIV.

Disclosure of HIV status is a multifaceted and often distressing process for PLHIV, as it involves the fear of stigmatization and discrimination. Numerous studies have documented the psychological and social complexities surrounding HIV status disclosure, with many individuals opting for concealment to avoid social exclusion.[8] Various factors, including perceived stigma, social support, and cultural context influence the decision to disclose one's HIV status.[9] This phenomenological study aims to explore the lived experiences of PLHIV concerning their emotional responses and decisions surrounding disclosure, providing a deeper understanding of this critical issue.

Hope is an essential psychological resource for individuals managing chronic illnesses, particularly for PLHIV. Research has shown that hope can enhance psychological resilience, adherence to treatment, and overall well-being in individuals living with HIV.[10] This aligns with the research conducted by Siril *et al.*, which suggests that hope can enhance the quality of life for individuals living with chronic illnesses. A lack of hope is correlated with increased levels of depression and anxiety, which can further worsen the quality of life.[11]

Facilitating hope can be an important element of non-pharmacological interventions that can be utilized in the management of HIV sufferers. Beliefs and hopes are crucial in facing difficult situations and maintaining a good quality of life, as they help mitigate the psychosocial consequences of such conditions.[12] The relationship between hope and emotional responsiveness is central to the coping strategies employed by PLHIV, as hope can attenuate the negative effects of stigma and discrimination. This study will investigate how hope interacts with emotional responsiveness and stigma in shaping the lived experiences of PLHIV.

Despite advances in medical treatment and public health awareness, stigma remains a persistent barrier to the well-being of PLHIV. The impact of stigma is profound, affecting not only mental health but also the social and economic opportunities available to individuals with HIV.[13] Stigmatization often leads to social isolation, reduced access to healthcare services, and heightened emotional distress.[14]

Although many studies have addressed the impact of stigma on PLHIV, most studies have focused on psychosocial aspects separately, such as stigma or mental health. However, the relationship between emotional responses, disclosure of HIV status, stigma, and hope has not been explored in depth. Previous research has tended to ignore a holistic perspective that includes how these factors influence each other, especially from the perspective of the individual experiencing it directly. In addition, different cultural and social contexts, such as in areas with high levels of stigma, are often under-considered, so research results cannot always be applied universally. This research offers a new perspective for PLHIV regarding emotional responses, disclosure of HIV status, stigma, and hope. Focusing on individuals' lived experiences in specific social and cultural contexts, particularly in areas with high HIV stigma, can provide deeper and more contextual insights. With this approach, research can identify the need for interventions that are not only psychological in nature but also include social and emotional dimensions. This approach also opens up opportunities to develop empathy-based intervention strategies that are more relevant and effective for PLHIV.

Materials and Methods

This study used a descriptive qualitative design and a phenomenological approach. The sampling procedure utilized purposive sampling techniques with criteria-based selection. Inclusion criteria were: i) individuals diagnosed with HIV; ii) aged 18 to 60 years; iii) active members of the Community Peer Group Support Yayasan Pontianak Plus; iv) able to communicate effectively; and v) willing to participate in this study. Conversely, PLHIV experiencing adverse conditions, such as being in intensive care in a hospital or living alone without family, were excluded.

The data were collected via in-depth interviews utilizing participant-specific guidelines and direct observation of the subjects. The interview guidelines were validated by experts in HIV nursing to construct key questions. A qualitative study expert also provided positive feedback on the interview guidelines. The interview focused on the thoughts and feelings of the participants, specifically about their emotional responses when they were diagnosed with HIV. Each interview took about one hour and was conducted in the Yayasan Pontianak Plus office. Each participant was interviewed individually as a form of consideration for their privacy and convenience, and field notes were made during interviews.

The data were analyzed using *verbatim* reports by Collaizi's method, which included: i) reading the transcript of the interview and field notes to obtain a general picture of the participant's experience about emotional responsivity, openness, stigma, and the hope for the future; ii) reading the transcript repetitively to find the key or significant statements from participants; iii) searching for meaning in the participant's key statement; iv) grouping each meaning obtained into themes (researchers made a theme analysis table consisting of keywords, categories, themes, and subthemes); v) integrating all the themes that emerged into a comprehensive description and verifying the transferability of the data (the themes that emerged have been discussed with two supervisors and two experts to create a comprehensive description as a clear statement); vi) validation of the results through member checking as a means of confirmability.

To support confirmability, the authors, who had no prior relationship with the participants, conducted all interviews using a consistent guide, and multiple researchers analyzed the data.

Researchers presented the analysis results to the participants to gather their feedback on the findings. Trustworthiness was established through multiple methods, including creating *verbatim* reports for each session and having each patient confirm the credibility and validity of the data and analyzed results. To ensure transferability, the researchers employed methodological triangulation, which involved conducting interviews, observations, and documentation throughout the interview process.

Ethical approval for this study was obtained from the Ethics Committee of the Faculty of Medicine Universitas Tanjungpura (date of approval: 29 May 2024, number: 6186/UN22.9/PG/2024). Prior to the survey, participants were provided with a detailed explanation of the study protocol, and informed consent was obtained through agreement documents. They were made aware of their right to decline participation and their freedom to withdraw from the study at any time. All data collected were kept confidential and anonymous.

Results

The study comprised 12 participants whose characteristics exhibited diversity in age, gender, marital status, transmission risk factors, Antiretroviral (ARV) therapy usage, illness duration, occupation, and educational attainment.

Table 1 presents the characteristics of the respondents. The participants included 9 males and 3 females, with ages ranging from 23 to 54 years. Their occupations varied: 1 participant was a junior high school student, 5 were senior high school students, 1 was a D4 student, and 5 were undergraduate students. Most respondents, with varying ages and occupations, had risk factors associated with transmission, primarily due to the use of injection needles or sexual intercourse. Moreover, most respondents had been receiving ARV treatment for an extended duration, demonstrating their capacity to adapt to the challenges encountered.

Theme 1: emotional responses to HIV confirmation

Upon receiving their HIV diagnosis, participants exhibited a range of emotional responses. One participant demonstrated acceptance of his/her condition, while others displayed signs of denial. Below are selected quotes from interviews conducted with the participants:

Acceptance

Acceptance is a phase of grieving. Participants said that they embrace the disease as if it were a matter of faith. One participant stated:

"*God wants me to do whatever I want… In the end, I accepted it as it is, but there is still a plan… finally, I thought about committing suicide at that time.*" (P8)

Denial

Denial is the first phase of grieving. Most of the participants expressed disbelief about their disease. They stated that they never expected to have HIV. The forms of denial varied among them; some felt shocked and scared, struggling to comprehend what had happened. Others even expressed suicidal thoughts. Here are some quotes from the interviews:

"*Wow… like a bolt of lightning in broad daylight… shocked, down. Eee closed me off at first.*" (P1)

"*The feeling was the same as most of my friends, sad. Is this like despair?*" (P2)

"*Hm.. in 2007, I was still at the stage of not accepting the status, right?*" (P3)

"*Like being struck by lightning, hmm, like I didn't expect it.*" (P5)

"*Even then, I was scared.*" (P6)

"*At first I felt very down… my feelings couldn't accept it at that time.*" (P10)

"*So at that time I was shocked, sis… I thought maybe I shouldn't get married anymore.*" (P12)

Theme 2: disclosure status

The results of this qualitative study exploring HIV status disclosure among PLHIV reveal a diverse range of experiences and decisions regarding openness about their condition. The data from in-depth interviews with 12 participants underscores how factors such as relationship dynamics, family support, and personal coping strategies shape the disclosure process. The study found that while some individuals disclosed their status to their partners, families, and communities, others opted for secrecy, often driven by fear of stigma or rejection. This theme consisted of two subthemes, *i.e.*, undisclosed and disclosed.

Several participants expressed a willingness to disclose their HIV status to their partners, particularly before entering long-term relationships or marriage, emphasizing that honesty was crucial. The participants stated:

"*Before getting married, I was open with my partner.*" (P3)

"*I informed my partner about my status…*" (P7)

Another participant emphasized the community's ethical responsibility to disclose their HIV status and stated:

"*Thank God, I know now that, generally, we in the community are required to be informed.*" (P1)

"*I opened my status to my friend in the community.*" (P8)

On the other hand, some participants open their status to family core members:

"*At first the family didn't know, but after a while my mother found out, but thank God she was supportive…*" (P7)

"*Then I opened my status to my parents and opened it to my siblings, too. But thank God, my family accepted it, even supported it… supported, so maybe from there my condition quickly improved even though it was gradual.*" (P5)

"*I opened my status to my father, meanwhile my father was unhealthy, he shocked after listening to the fact.*" (P8)

Some family members were initially shocked, but afterward, participants reported that their families, particularly their parents, provided strong support. This support appeared to positively impact their well-being, as one participant mentioned that his/her health improved after receiving emotional and practical backing from their family. The role of family acceptance emerged as a significant factor in fostering resilience and hope among PLHIV.

In contrast, a few participants chose not to disclose their HIV status to anyone, including their family members. These individuals chose to conceal their status to guard against potential stigma, discrimination, or emotional distress. They stated:

"*No one in my family knows…*" (P12)

"*Regarding my status, I keep everything to myself…*" (P8)

Theme 3: stigma towards PLHIV

This theme comprises 2 subthemes: sources of external stigma faced by participants and forms of HIV stigma received by participants both in the environment and in health services. Here are some instances from interviews with participants experiencing stigma due to cultural beliefs:

"*You know, our country, specifically in this area, has a strong culture that believes HIV is a cruise…*" (P4)

"*The moral values are opposite with factors that transmit HIV, so there will be more stigma for me…*" (P9)

The other subtheme is "forms of HIV stigma received by participants", which are: social stigma, institutional stigma, and healthcare stigma. Some interview participants reported experiencing social stigma:

"*Many people in here believe that HIV is a disease caused by a great sin.*" (P8)

"*People worry about interacting with people with HIV.*" (P12)

One participant discussed the issue of institutional stigma, stating:

"*So hard to apply for work because the institutions have a specific required health status.*" (P3)

Healthcare stigma experienced by participants was a common theme. Some participants expressed the following:

"*Once the nurse asked, 'Are you HIV positive?', I was confused and didn't know how to react, like…hmmm… I panicked.*

Why was the nurse doing this, right?" (P2)

"*Sometimes, health professionals are still giving us stigma and discrimination. They looked at me disrespectfully. I didn't know if it was a joke or not, but it felt like that.*" (P6)

"*I got a bad response from public health service when I took my ARV. It makes me worry every visit to healthcare.*" (P11)

Theme 4: hope and desire for the future

This theme encompasses two subthemes: personal hopes and hopes for others. The personal hopes of PLHIV include various aspirations, such as achieving a better quality of life, receiving strong social support, and experiencing a reduction in stigma and discrimination. Also, PLHIV hopes to live normally, carry out daily activities without social or medical obstacles, and have equal opportunities in the workplace, education, and social life.

This is demonstrated by the results of interviews conducted with several participants, detailed as follows:

"*That's why it shouldn't be a matter of discrimination; it should be a matter of friends getting their right to get a job... I mean, it should be easier; there should be an easy system to make it easier.*" (P6)

The hope for others includes advancements in treatment technology that will enable better infection control, improve health, and extend life expectancy. This is supported by the results of interviews with several participants:

"*I hope my spouse doesn't get infected and wants to do the test. Even if it's positive, just take ARV early and don't be ashamed anymore.*" (P1)

"*So that we can live a normal life even though we have HIV, like ordinary people... there is still hope that the ARV stock will be subsidized by the government because the drugs are expensive.*" (P2)

"*Yes... the hope is to survive, that's for sure, and secondly, but this can't be done, it can't be done… I don't know if research can lead to a cure, thank God. If that's not the case, try to keep taking medicine and working.*" (P4)

"*Hopefully you stay healthy, don't ever get tired of taking medicine.*" (P11)

Discussion

The study discusses participants' varied emotional responses after receiving an HIV diagnosis. These responses span multiple stages, from denial to acceptance, reflecting the complexity of individuals' psychological experiences in reaction to challenging health conditions. These findings align with literature suggesting that many factors, including social support, personal understanding of the disease, and cultural context, often influence emotional responses to a chronic disease diagnosis.[15]

Based on the interviews, one of the participants (P1) described his experience very powerfully: "*Like being struck by lightning in broad daylight... shocked, down. Eee shut down at first*". This statement describes a common shock reaction following diagnosis, in which individuals feel devastated and unprepared to face the new reality. A similar reaction was also expressed by P5, who stated, "*It was like being struck by lightning... didn't expect it*". These responses suggest that the beginning of the emotional journey is often marked by feelings of profound helplessness and uncertainty, which can result in individuals withdrawing from necessary social support.

Apart from feelings of shock, sadness and hopelessness were dominant themes in interviews with several participants. P2 expressed, "*The feeling was the same as most of my friends, sad. Is this like despair?*". This sadness may be caused by the strong social stigma towards HIV, which often leads to reduced self-esteem and feelings of hopelessness.[16] In this context, the emotional reactions shown by participants can be understood as a reflection of the collective experience of individuals facing an HIV diagnosis in a society that still has negative prejudices towards the disease. The process of accepting HIV status is also an important part of the discussion. P3 indicated that in 2007, he was still in the "not yet disclosed" stage. This acceptance process often takes a long time and can be hampered by external factors, such as a lack of social support or adequate information about HIV.[17] P8, who stated, "*I accept it, but there are still plans... in the end, I thought*

Table 1. Characteristics of respondents.

Participants	Age	Sex	Marital status	Risk factor of transmission	ARV consumption	Duration of illness	Occupation	Level of Education
P1	47	Male	Married	IV Drug user	ARV	18 years	Salesman	High School
P2	44	Male	Married	IV Drug user	ARV	20 years	Administration	High School
P3	37	Male	Married	IV Drug user	ARV	15 years	Seller	High School
P4	38	Male	Single	Sexual intercourse	ARV	3 years	Teacher	Bachelor
P5	39	Female	Married	Sexual intercourse	ARV	14 years	Housewife	High School
P6	32	Male	Married	IV Drug user	ARV	16 years	Private sector employee	Bachelor
P7	30	Female	Married	Sexual intercourse	ARV	6 years	Housewife	Bachelor
P8	28	Male	Single	Sexual intercourse	ARV	5 years	Private sector employee	Bachelor
P9	34	Male	Married	Sexual intercourse	ARV	2 years	Teacher	Bachelor
P10	54	Female	Married	Sexual intercourse	ARV	14 years	Private sector employee	Junior High School
P11	23	Male	Single	Sexual intercourse	ARV	3 years	Private sector employee	Diploma
P12	24	Male	Married	Sexual intercourse	ARV	6 years	Singer	High School

about committing suicide", indicated that despite efforts to accept the diagnosis, there is still a deep inner conflict that can trigger negative thoughts.

Fear of the future also emerges as a significant emotional response. P6 expressed, "*At that time, I was scared*", reflecting anxiety about the consequences of the diagnosis. This fear is often related to the stigma attached to HIV, which can make individuals feel isolated and helpless in facing daily life challenges.[18] This suggests that psychological support and understanding from those closest to them are essential to help individuals overcome fears and rebuild their self-confidence. Overall, the results of this study emphasize the need for emotional and psychological support for PLHIV to help them through the complex adaptation process after diagnosis. The range of responses, from shock to acceptance, reflects a long and often difficult emotional journey. Therefore, healthcare providers must understand these emotional dynamics and provide appropriate interventions to help individuals manage their emotional responses.

Most of the participants involved in this study indicated a desire to disclose their HIV status to a partner before entering a long-term relationship or marriage. This aligns with findings that state that honesty in romantic relationships is very important for building trust and openness.[19] For example, P3 stated, "*Before getting married, I was open with my partner*". This suggests that some individuals feel an ethical obligation to be honest with their partners, which is the foundation of a healthy relationship.

Support from family also plays an important role in the disclosure experience. Some participants reported that although they initially felt fear and worry from their family upon revealing their HIV status, particularly from their parents, the emotional and practical support from their family after the initial shock significantly improved their well-being. P7 emphasized, "*At first, the family didn't know, but after that, my mother found out, and thankfully she was supportive*". These findings are in line with previous research, which shows that family support can help PLHIV overcome the challenges they face and contribute to improving their health and well-being.[20]

On the other hand, some participants chose not to reveal their HIV status to anyone, including family members. The decision to keep this status is felt as a way to protect oneself from stigma, discrimination, or emotional burdens. One participant asserted, "*No one in the family knows about my condition*", reflecting a fear of negative consequences such as rejection or social isolation. Previous research also shows that HIV-related stigma often acts as a barrier for PLHIV to share information about their health status.[18]

These varying experiences of disclosure and confidentiality highlight the complex and highly personal nature of disclosing HIV status. For some participants, disclosure resulted in greater emotional support and strengthened relationships. In contrast, for others, the decision to remain silent was influenced by a desire to avoid stigma and protect their social status. These findings demonstrate the importance of healthcare providers and support networks respecting individual choices and offering interventions tailored to the unique emotional and social contexts PLHIV faces as they navigate their disclosure decisions.

Stigma towards People Living With HIV/AIDS (PLWHA) remains a significant challenge in their experiences while undergoing care and treatment. This stigma arises not only from the general public but also from health workers who are supposed to provide the necessary support and care. Interviews with participants revealed that they often feel discomfort and confusion when interacting with health workers who exhibit discriminatory behavior. One participant (P2) stated, "*Once the nurse asked, 'Are you HIV positive?' I was confused and didn't know how to react… hmmm… I panicked*". These reactions show how deeply stigma affects the emotional state of PLWHA, which can worsen their mental health.

P6's statement also reinforced this condition: "*Sometimes, health professionals still provide stigma and discrimination. They looked at me with disrespect. I don't know if it was a joke or not, but it felt like that*". This condescending attitude from health professionals not only impacts the relationship between PLHIV and healthcare providers but can also hinder their access to adequate care.[21] Distrust of the health system can make PLHIV reluctant to seek care, potentially worsening their overall health.

Based on previous research, stigma towards PLHIV can result in avoidance of health services, resulting in negative consequences for disease management and quality of life.[22] Therefore, it is important for health institutions to provide training and education for health workers regarding sensitivity to stigma issues and the importance of creating a supportive environment. Raising awareness of this stigma can help reduce the discrimination experienced by PLHIV and encourage them to be active in managing their health. Efforts to educate health workers and increase public awareness about HIV/AIDS must be carried out continuously to reduce stigma and support the mental and physical health of PLHIV.

Discussing the hopes of PLHIV reveals that, despite facing numerous challenges, they have strong aspirations to enhance their quality of life and combat social stigma. This hope includes the desire to live normally and carry out daily activities without obstacles, both from a social and medical perspective. This is reflected in participant statements, such as P1, which emphasized preventing transmission to partners and having the courage to get tested. This statement shows the awareness and responsibility of PLHIV in maintaining their health and that of others. Another participant, P2, expressed his hope of getting government support in providing affordable ARV drugs. This indicates that while PLHIV aspire to live normal lives, they also understand the importance of accessing adequate treatment to achieve this goal. Support from the government and society in reducing medical costs can improve the quality of life of PLHIV.[23] In addition, P4's expression of hope to continue fighting and working demonstrates the resilience and enthusiasm of PLHIV to keep living despite facing limitations.

Participants also expressed concerns about stigma and discrimination, as demonstrated by P6, who asked for easier access to rights such as employment. This is in line with previous research, which shows that social stigma can be a significant barrier for PLHIV in achieving their full potential, both at work and in social life.[22] Lastly, the hope of PLHIV to remain healthy and committed to treatment, as expressed by P11, emphasizes the importance of social support in their journey. Support from family, friends, and the wider community can be a determining factor in improving PLHIV's hope and quality of life.[21] Overall, the hopes expressed by PLHIV reflect a strong desire to adapt and live a meaningful life despite existing challenges.

Infectious diseases must be taken seriously to control their transmission and prevent community spread.[24] Families are integral to the lives of individuals with infectious diseases, as they are usually the patient's nearest support system. Their support is essential for helping the patient maintain a healthy lifestyle.[25]

This study had some limitations. Due to its qualitative design and the sample primarily consisting of Melayu and Dayaknese ethnic patients, the findings may not fully represent other populations. Additionally, as this small study was conducted in a single practice, it may not accurately reflect the opinions of all individuals living with HIV nationwide.

Conclusions

This phenomenological study reveals the complex interplay between emotional responsiveness, hope, stigma, and the disclosure of HIV status among PLHIV. Participants demonstrated varying levels of emotional acceptance, with some experiencing initial denial or physical symptoms that impacted their emotional state. Motivations for treatment adherence were often rooted in internal and external support sources. Disclosure of HIV status was influenced by personal, familial, and social dynamics, with some individuals choosing openness while others opted for secrecy due to fear of stigma. The study also highlighted the role of health information, decision-making processes, and the utilization of healthcare services, as well as the critical role of family caregivers in the care of PLHIV. Barriers to accessing care, including challenges related to healthcare services and employment, were significant. Still, the presence of personal hope and external support systems emerged as crucial factors in overcoming these obstacles. Addressing stigma and fostering support systems is essential for improving the emotional and physical well-being of PLHIV. Further studies involving diverse ethnicities are necessary to gain a broader understanding; this should be a focus for future research.

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