

Lifestyle and Problems of HIV Sufferers in Surabaya: Phenomenological Study

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ABSTRACT

People living with HIV AIDS (PLWHA) are someone who experiences physical, and psychosocial life threats, and social problems such as anxiety and depression. PLWHA are also very vulnerable to stigma which results in community discrimination. The complexity of the problems experienced by PLWHA requires special attention to be resolved immediately. The purpose of this research was to explore the lifestyle and problems of people living with HIV AIDS (PLWHA). This research uses a phenomenological study. The ethical test was obtained from STIKes William Booth. There are 5 informants selected based on the purposive sampling technique. The data was taken by means of an open-question questionnaire. Each respondent was given questions using the interview method and then recorded. There were 2 main topics that were asked, the first topic is the initial condition of being diagnosed with HIV and the secondary topic is the lifestyle and current problems. The results of the interviews found that the sample had suffered from HIV 5-8 years ago due to risky behavior. Diagnosed because he felt the symptoms of a disease that did not cure. Psychosocial complaints stem from internal feelings such as feelings of guilt, having no future, and fear of death. In addition, the problem of external stigma greatly threatens social relations activities with other people. Continuous social support is a basic need. Spending time alone and working became daily activities. HIV community groups are difficult to reach because of distance. Activities do not vary due to physical constraints such as the effects of medication and co-morbidities. Some have tried to exercise but are less successful. Need the right way to reduce the physical constraints felt by PLWHA, psychosocial support is needed to change the mindset of PLWHA. Sustainable programs that can reduce community stigmatization are the key to changing the quality of life of PLWHA.

Keywords: HIV; lifestyle; problems

INTRODUCTION

People living with HIV AIDS (PLWHA) are someone who experiences physical and psychosocial life threats (Kurniawan et al., 2022). Physical complaints are caused by changes in health conditions which often make PLWHA unable to carry out normal activities (Algarin et al., 2020). In addition to physical complaints, social problems such as anxiety and depression are common for PLWHA. PLWHA are also very vulnerable to stigma, resulting in community discrimination (Gottert et al., 2018). Discrimination exacerbates unpleasant actions when they work, go to school, or do other activities. This event arises when seeking health services (Kurniawan et al., 2022).

The complexity of the problems experienced by PLWHA requires special attention to be resolved immediately. This is reinforced by the increasing number of PLWHA in Indonesia yearly (Tsuyuki et al., 2019). Recent data shows an increase in PLWHA to more than 550,000 people. This increasing number has led to many studies related to the treatment of PLWHA, but in reality, the problems of PLWHA have remained the same (Kurniawan et al., 2022).

The lifestyle of PLWHA and their problems need to be observed further to determine a better direction for problem-solving. Previous research studies tended to see PLWHA as part of the problem by giving unilateral treatment without examining it in depth (Watson et al., 2019). This study aims to reveal the lifestyle and actual problems experienced by PLHIV so that when problems arise, the direction of policymaking becomes more optimal.

METHOD

This study uses a qualitative design with a phenomenological approach focusing on the lifestyle experiences and problems of people living with HIV AIDS (PLWHA). The sample of this research is people living with HIV in Surabaya. This research uses purposive sampling. Sample criteria in this study were PLWHA, who had been infected for at least 3 years and were over 21 years old, regardless of gender, sexual orientation, marriage, and economic status. This research was conducted at a non-governmental organization (NGO) in Surabaya, Indonesia. Data saturation was reached on the 4th informant, then added 1 for data validation.

The data collection procedure uses an interview guide that was made beforehand to limit the subject matter to the direction it should be. The interview guide consists of demographic data and questions. An audio recorder assists in the data retrieval process. Field notes covered all verbal and non-verbal cues during the interview. Data analysis uses data credibility triangulation involving experts, sources, and media who review the results of verbal and non-verbal recordings and notes.

RESULT

The profiles of the informants

1. Ms. L is a 40-year-old heterosexual woman. She works as a Commercial Sex Worker. He is not married but has been married (divorced). He has no children. He is a graduate of Senior High School. He was diagnosed with HIV in 2018.
2. Ms. Y is a 31-year-old heterosexual woman. He works in the home leather craft industry. He is not married yet. He has experienced intercourse without contraception. He also has tattoos on several parts of his body. He is a graduate of Senior High School. He was diagnosed with HIV in 2017.
3. Mr. A is a 40-year-old bisexual man. He works as a customer service at a bank in Surabaya. He was once married but divorced. He has children. She had experience of having unprotected sex with both men and women before marriage. He is a graduate of vocational higher education. He was diagnosed with HIV in 2015.
4. Mr. Ju is a 32-year-old transvestite. He worked as a tailor and a nightclub singer. He is not married yet. She has experience having unprotected sex with men. He is a graduate of Senior High School. He was diagnosed with HIV since 2016
5. Mr. Jo is a 30-year-old homosexual man. He works as an environmental specialist. He is not married yet. He has experienced intercourse without contraception. He never had anal sexual intercourse. He graduated with a bachelor's degree in environmental engineering. He was diagnosed with HIV in 2017.

Findings on Theme 1: Initial condition diagnosed with HIV.

This theme confirmed the initial condition of the first time the interviewee was infected with HIV. Understanding informants regarding HIV risk behavior and partner protection will encourage someone to seek clarification of their status. Some also do so because they have been affected by the signs that appear in HIV patients that affect their health (Stadtler et al., 2021). Based on the opinion of Kurniawan et al. (2022) stated that most people with HIV will take an HIV test if they have knowledge about the disease, know a relative has died from complications of HIV/AIDS, or are aware of themselves the risky behavior they are carrying out. The first theme is divided into 2 sub-theme questions as follows.

Subtheme 1: Have you ever done risky behavior?

"I have had sex with several people since I was 18 years old; sometimes I have intercourse using a condom, and sometimes I don't because it depends on my client's request. I don't know; sometimes, there is an urge not to use a condom. To be honest.... I'm more satisfied with not using it. I know the risks involved, but how can I refuse when in that situation? I must be able to satisfy the client as well. Because, after all, my work is like this." (Ms. L)

"Risk behavior that I know.... I've had sex with some of my dates. When having sex, I don't use a condom because I'm not satisfied, and it feels weird. Besides that, my partner doesn't like it either. I also like to use tattoos; tattoos are beautiful for my body. I do tattoos at tattoo artists I know and am skilled at. I never know whether they changed the needle, but it is clear that the results are good, so I want to." (Ms. Y)

"I have had sexual intercourse. The risky relationship that I did was anal sex and oral sex. When doing that, I do not want to use a condom. I know it's risky, but what else can I do?" (Mr. A, Mr. Ju, Mr. Jo)

Subtheme 2: Reasons for doing HIV testing?

"I checked myself because my partner was then diagnosed with HIV. His friend advised him to do the test because he started showing mild symptoms with frequent intensity. So, he did the test himself, and it came back positive. He texted me to let me know and advise me to get an HIV test too." (Ms. L, Mr. A, Mr. Jo)

"I checked myself because I was often sick. Initially, symptoms such as diarrhea and fever but over time, can be 3-4 times a month. Then it's getting harder and harder to heal. I gave medicine, and it didn't stop. Usually, it takes 2-3 days to heal, but it's been getting worse for weeks, so my weight has dropped dramatically. Many of my colleagues say I am getting thinner." (Ms. Y., Mr. Ju)

Findings about theme 2: Lifestyle of patients and problems that arise.

This theme confirms what HIV patients do daily and what problems arise when carrying out these activities. The daily activities of HIV patients are certainly different from people in general. Most HIV patients have passive behavior and close social relations with their environment. Some become unproductive and stay home (Sanchez & Kaul, 2017). A small proportion of people with HIV are still active, as usual. This is certainly not easy because the problems arising from physical and psychological obstacles create significant obstacles (Rendina et al., 2017). Physical and psychological problems experienced, such as illness and anxiety disorders ranging from mild to severe, can appear in HIV patients (Ayano et al., 2020). Psychological problems are still the biggest determining factor and have a reciprocal impact, like a domino factor that worsens conditions (Garrido et al., 2017). This second theme is divided into 3 sub-theme questions as follows.

Subtheme 1: What activities do you routinely do every day?

"I am a commercial sex worker. In the morning, I spend my time sleeping at home. It's called a night worker. What else can you do? So, if you sleep in the morning. I spend my time at night doing activities as a prostitute, not every day, but 1 week can be 3-4 times. Sometimes it's crowded, sometimes it's quiet, tenants. Every day I do like that. I rarely do social activities such as meeting residents. Because many residents already know that I am a prostitute, they are lazy to listen to what people are saying. There is no activity other than work. Most of the time, I get together with my friends and even those who are prostitutes. I haven't prayed in a long time." (Ms. L)

"Every day I work. I spend my routine working. I prefer to spend my time alone working. Except for Sundays, I usually go out with my relatives and friends for vacation. I never exercise and limit social activities with people around my neighborhood. I still pray sometimes." (Mr. A, Ms. Y, Mr. Ju, Mr. Jo)

Subtheme 2: What physical problems do you experience every day?

"What makes the problem are the side effects that arise from ARVs, sometimes there is a ringing sound in my ears which disturbs my sleep, and sometimes the sound disappears, but my head feels sleepy and heavy." (Ms. L)

"I also sometimes feel a bit sore and have chills in my body." (Ms. Y)

"I feel that there is an effect of having trouble sleeping even though I don't feel dizzy or anything wrong. I also often wake up at night, interfering with my morning activities. The side effects of the treatment were very bad in the first to the second month." (Mr. A, Mr. Ju)

"Apart from that, I also felt lazy to eat, and my stomach felt bloated even though I didn't eat." (Mr. Jo)

Subtheme 3: What psychological problems do you experience every day?

"Every day I isolate myself, especially from people who know about my condition. I don't know what to do. I sometimes feel sad when." (Ms. L)

"I was depressed. I even contemplated suicide. I get angry easily when someone asks about my condition. It happened to me. If I'm alone in my room, I always think about how productive my life was before." (Mr. A, Mr. Ju)

"Until now, I am still traumatized by gatherings, let alone interacting directly with my colleagues." (Ms. Y)

"Yes, I was depressed because I felt I was sentenced to death. But luckily, I have colleagues who help me. I often consult religiously too. There are times when I'm alone and regret what I did." (Mr. Jo)

DISCUSSION

In general, people with HIV AIDS (PLWHA) are familiar with the risk factors/behaviors that cause them to be infected with HIV, such as free sex, unprotected sex, and the use of alternate/unsafe needles (for example, body tattoos) (Kurniawan et al., 2021). PLWHA also realize the importance of tests to determine their condition and when to start the test. The most common reason PLWHA engages in risky behavior is because of personal needs. The trigger factor for someone being infected with HIV is unsafe sexual behavior such as anal sex, oral sex, or sex without a condom (Anakwa et al., 2021). Knowledge and perception may not be able to be applied because of needs and desires that are difficult to contain. (Algarin et al., 2020). Kurniawan et al. (2020) highlighted risky sexual patterns as a common cause of HIV. In addition, it was also explained that HIV could be transmitted using alternate needles, including drug use and tattooing (Gottert et al., 2018). Rendina et al. (2017) said that most people with HIV applied for a test because their partner, currently or previously, was affected by HIV positive (Kurniawan & Sulistyorini, 2019).

PLWHA conducts HIV tests mostly due to cases of direct exposure to HIV patients, such as having sex with HIV patients. Another thing that motivated the examination was the emergence of co-morbidities such as fever, ongoing diarrhea, and weight loss. Some also said that there was social support that facilitated HIV testing. Social roles are important in motivating PLWHA to take HIV tests. Knowing that a relative or closest person is diagnosed with HIV is a factor that encourages someone to take an HIV test (Ayano et al., 2020). Previous knowledge about HIV, including modes of transmission, risk factors, and early signs and symptoms, makes a person want to check himself (Garrido et al., 2017). The presence of HIV/AIDS advocates is an important factor because they help with health education and destigmatization, safe sex practices, regulation of injecting drug use, routine tests, and medication adherence (Sanchez et al., 2017). Watson et al. (2019) stated that PLWHA could acquire self-advocacy skills as they promote health education, prevention, and treatment.

PLWHA often spend time with the work activities they do. Many of them do not participate in social activities in the neighborhood where they live. Some PLWHA intentionally withdraws from the environment because of anxiety about social stigma. Some of them still exhibit the behavior of worship, although not routinely. Lifestyle can affect adherence to HIV treatment and increase opportunistic infections and death (Endrian, 2021). Lifestyle changes are needed and are part of managing HIV patients (Rendina et al., 2017). Spirituality activities can help improve the quality of life through optimistic values that can impact stressors through prayer and surrender (Gottert, 2018). Lifestyle changes are necessary if the goal is to be healthy and live longer. Kurniawan et al. (2020) stated that lifestyle changes are part of managing HIV/AIDS.

The physical problems experienced by PLHIV are entirely due to the side effects of taking ARVs. Some complained of dizziness and weakness, but some complained of difficulty sleeping/decreased sleep quality. Some PLWHA said that these effects only appeared in the first few months. PLWHA require lifelong treatment to maintain their health and are initially faced with the side effects of treatment. An informant delayed taking ARVs because of known side effects. Nausea and vomiting, hot flashes, abdominal pain, and nightmares were noted as side effects (Rendina et al., 2017). One of the problems for HIV sufferers who consume ARVs is drug side effects. Problems such as anemia causing dizziness and weakness, lack of energy and difficulty focusing, nausea, and rashes often occur in group one combination (Algarin et al., 2020). It takes time to adjust to the side effects of ARVs. Headaches, dizziness, nausea, vomiting, fatigue, lack of energy, difficulty sleeping, digestive discomfort, skin rashes, and nightmares are some of the common side effects of ARV treatment (Algarin et al., 2020).

Most PLWHA says they experience depression with their condition. Some expressed a wish to end their life or felt it was over. Some PLWHA also shows irritable behavior and regret their condition. Some PLWHAs seek solutions to their psychological problems by seeking support from the social environment. Social stigma seems to be the biggest challenge PLWHA will experience (Herawati et al., 2021); and is an obstacle to disclosing the status of HIV sufferers (Algarin et al., 2020). A support group's presence will positively impact the lives of PLWHA (Kurniawan et al., 2022), including lifestyle changes, coping, and medication adherence (Anakwa et al., 2021).

CONCLUSION

Knowledge and risky behavior in HIV sufferers (PLWHA) will be considered in HIV testing. Direct interaction with HIV patients shows an increased desire to carry out examinations. Recurring symptoms that occur in the body, such as weight loss, fever, and ongoing diarrhea, can be additional factors that influence the desire of PLWHA to have their condition checked. The lifestyle of PLWHA is mostly limited to doing work activities and rarely socializing with the surrounding environment. PLWHA do not want to socialize because they fear the stigma that arises from society.

PLWHA are more likely to choose associations with colleagues or certain groups. PLWHA recognizes the importance of support groups. They are willing to follow changes that will help them to be healthy, including changes in lifestyle and sexual patterns. Many physical problems in PLWHA arise due to the effects of HIV drug administration (ARV). Psychological problems such as depression and suicidal thoughts often occur in PLWHA. Some of the PLWHA choose to try to seek social support, one of which is a health worker. Social assistance from the environment is important in educating the public about HIV prevention and transmission, caring for newly diagnosed clients both physically and psychologically, and assisting clients on the road to recovery and wellness.

There is a need for wide-scale promotion of safe sex practices and health education regarding HIV testing, HIV transmission, and HIV stigma. Information dissemination should include HIV patients as well as at-risk and non-risk communities. It is necessary to create social groups that shelter HIV patients so that social support does not stop at the family scale but also at the wider community. Religious institutions, such as religious leaders, can be considered involved in dealing with the psychological problems of HIV patients.

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