

Anxiety in Housewives Infected with HIV

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ABSTRACT

This study aims to reveal the picture of anxiety in 2 housewives infected with HIV/AIDS from their husbands and the factors that influence it. This research uses qualitative method with case study approach. Data obtained through interviews and analysed using content analysis. Anxiety on the first subject S is indicated by thoughts about death and concerns about stigma and discrimination from the environment that made subject to stay away from her environment. In the second subject KL, anxiety is indicated by thoughts about death, fear of losing infected family members, worry about stigma and discrimination resulting in the subject becoming irritable, confused, having trouble sleeping, losing appetite, losing enthusiasm for life and not interested in planning for the future. Factors that influence anxiety in both subjects are physical condition, partner's HIV status, stigma, history of psychiatric illness and social support. The results of this study are expected to be the attention of health care institutions and become a reference in order to increase education about the importance of support for HIV/AIDS patients to avoid stigma and discrimination against PLWHA. As well as educating the public regarding reducing risk factors through a healthy lifestyle.

Keywords: anxiety, HIV/AIDS, house wives

Introduction

AIDS (Acquired Immune Deficiency Syndrome) is not a single disease but is a syndrome caused by the Human Immunodeficiency Virus (HIV) (Whiteside, 2008) which invades the body's immune system and causing the sufferers to experience deficiency of body resistance so they are very easily infected with various diseases (Kemenkes RI, 2017). Not everyone infected with HIV will end up with AIDS, but untreated HIV infection will lead to AIDS. In Indonesia, the AIDS case was first discovered in Denpasar on April 15, 1987. Since then the number of AIDS patients has been increasing almost every year. Directorate General of Disease Prevention and Control Ministry of Republic of Indonesia reported in 2017, HIV/AIDS is spread in 80% of cities in Indonesia.

The profile of AIDS cases in Indonesia shows that the highest AIDS cases are experienced by non-professional employees followed by housewives (Kemenkes RI, 2017). Thus, housewives are a vulnerable group to be infected with AIDS. Yulianti (2013) stated that generally they are infected by their husbands who change sexual partners or because they are drug addicts. Lack of knowledge and awareness of housewives about HIV/AIDS makes it easier for them to be infected with the virus. Yulianti (2013) mentions that another factor that makes it easier for housewives to get HIV/AIDS is the potential for sexual violence against women, especially in the household which increases the likelihood of sexually transmitted infections (STIs) including HIV/AIDS.

In particular, being diagnosed with HIV/AIDS can cause various adverse impacts to occur. Armiyati, Rahayu, and Aisah (2015) found that being diagnosed with HIV/AIDS may leads to numerous consequences, such as: feeling shock, fear, anger, irritation, shame, sadness, and disbelief, some



sufferers have difficulty in social relations, feel awkward, embarrassed and confused when hanging out with her friends. Other research by Ahdiany, Widiyanti, and Fitria (2017) mentions the psychological impact on PLWHA (ODHA) such as: over thinking about death, sleep disturbances, anxiety, isolate themselves from their environment because they think they will die soon, most of them also fear of the pain that may be experienced, and anxiety will die soon, anger at the past and fear of the future.

Study conducted by Ossie, Ahmad, Prabandari and Hakimi (2017) explained the condition of housewives living with HIV/AIDS which shows that they often think about death, have a low desire to live and feel better off dead, some cannot accept reality and feel ashamed and worried about being considered naughty women, being ostracized, humiliated and avoided so they hide their illness comes from their family and people around them, therefore they often lie when taking medicine, go to the hospital and lie when not breastfeeding, especially some of them choose not to seek treatment instead of being depressed and always lying, some also feel inferior because they feel different from other patients who will recover while taking the medicine whereas they have to take the medicine for life.

Theoretical background

Acquired Immuno Deficiency Syndrome (AIDS) is an infectious disease characterized by failure of the immune system and caused by the Human Immunodeficiency Virus (HIV). AIDS and HIV are not the same; AIDS is best understood as the latest stage of the illness resulting from infection with HIV, characterized by the appearance of difficult-to-treat opportunistic infections and malignancies, which profoundly decreased immunity is unable to control (Watstein, 2003). Complicating factors are that people suffering from HIV/AIDS often experience loss of appetite, inability to eat due to infections of the mouth and throat, and failure to properly digest food. Additionally, the loss of labour and income that results from family members becoming ill may lead to there being less food available in the household (Whiteside, 2008).

Besides being known as a deadly disease, AIDS also has a broad psychosocial impact. The most common mode of transmission is sexual intercourse, followed by mother-to-child infection, sharing drug-injecting equipment, and contaminated blood or instruments in health care settings. Because transmission is mainly through sex or drug use and there is no cure, there is much prejudice and fear HIV/AIDS was and remains stigmatizing at an individual and national level (Whiteside 2008). HIV/AIDS symbolize "sin" and "evil" hence people living with HIV/AIDS are perceived as discredited individuals who has immoral characters Sontag (Liamputtong, 2013), hence HIV/AIDS has been seen not only as medical condition but also as stigmatized illness (Herek & Glunt in Liamputtong, 2013). It is not surprising that people living with HIV/Aids experience the stigma attached to HIV/AIDS and most experience discrimination in their daily lives (Apinundecha et al in Liamputtong, 2013).

Messie (2012) stated that people who feel discriminated against, they have self-stigma or internal stigma with feelings of shame, sadness, guilt and feeling inferior. This condition leads to high anxiety and stress thus they withdraw and stop participating in society because of their low self-concept. Ossie, Ahmad, Prabandari, and Hakimi (2017) stated that housewives with HIV/AIDS must live with anxiety in all aspects of their lives while also thinking about the continuation of their lives—especially regarding the future of their beloved child. They feel anxious about various negative stigmas in society, such as being infected with HIV means death or HIV/AIDS is a disease of naughty person.

Anxiety is a mood state characterized by negative aspects and symptoms of physical tension in which a person anticipates possible danger or misfortune in the future with feelings of worry, anxiety involves feelings, behavior and physiological responses (Barlow, Durand, & Hofmann, 20016). Anxiety involves emotional reactions that are more general or diffuse, beyond simple fears that are disproportionate to threats from their environment (Barlow in Oltmansns & Emery, 2013). Fear of uncertain future threats makes individuals more likely to flee (Lazarus, 1991).

The symptoms of anxiety will differ from one individual to another, and each of these symptoms has varying degrees from one another. Sue (Ahdarini, 2005) suggests several symptoms of anxiety, including:

1. Cognitive. The manifestation of cognitive symptoms in anxiety can vary from worry to panic. The strongest forms of cognitive symptoms can lead to belief in impending doom, preoccupation with unknown dangers, inability to concentrate or make decisions.
2. Motor symptoms that are reflected in actions or behavior. A person experiencing anxiety may exhibit random movements ranging from ordinary tremors to strong shaking of the body. ranging from ordinary tremors to strong shaking of the body.
3. Somatic, related to physical or biological reactions. Somatic changes can manifest as shortness of breath, dry mouth, cold hands and feet, diarrhea, frequent urination, fainting, palpitations, muscle tension, excessive sweating, increased blood pressure, and indigestion.
4. Affective, related to a person's feelings or emotions. The most severe form of anxiety is in the affective area. Feelings of extreme tension can become the terror of chronic anxiety. In this case a person feels uncomfortable and worries constantly about the impending danger, no matter how good things are at the time.

Description of anxiety in PLWHA is a complex bonding between anxiety symptoms and the factors that influence it. Several factors associated with anxiety in PLWHA includes: (1) Physical condition, as stated by Chaudhury, Bakhla and Saini (2016) who found that the more severe the HIV/AIDS disease, the lower the CD4 cell count, this can lead to an increase in the prevalence of depression and anxiety in PLWHA. (2) Duration of illness. Duko, Toma, Asnake and Abraham (2019) found that anxiety increases gradually with the duration of the disease and is positively correlated between the duration of the disease and the severity of anxiety, which means that the longer the illness is suffered, the higher the anxiety felt by the sufferer. (3) Partner's HIV Status. According to Evangelie and Wroe (2017), partners' HIV status can trigger anxiety, a sense of responsibility towards partners and concerns about HIV transmission can trigger anxiety about disclosure, with normative beliefs that someone should share their disease status. (4) Stigma. Several studies have identified that HIV/AIDS stigma is correlated with depression, anxiety and other psychosocial problems. Duko, Toma, Asnake and Abraham (2018) found that patients with stigmatized diseases know how other people perceive their illness, this is called stigma perception. Stigmatization causes limited social activities and because of their status, they begin to agree with the negative stereotypes associated with the condition. This process is referred to as internal stigma, which ultimately leads to psychosocial stress, depression, and anxiety. (5) History of mental illness. Patients with a history of previous mental problems are more prone to anxiety, in addition to HIV itself causing extreme symptoms (Duko, Toma, Asnake and Abraham, 2018). (6) Social Support. People living with HIV/AIDS are more prone to experiencing symptoms of depression and anxiety. Ahdhiani (2011) found that having support, especially family support, really helps to get a sense of security, satisfaction, comfort, and get emotional support which will reduce anxiety and make respondents feel valued.

Anxiety in HIV/AIDS infected wives is influenced by various factors and is manifested in various symptoms. According to Dalimoenthe (2011) housewives are generally infected with HIV from their husbands who commit adultery or because they use injecting drugs. Many of the wives only found out about HIV disease after their husbands died, the wives were then faced with the condition as people with HIV, widows or single parents (Indradjaja, 2013). Housewives who are infected with HIV through their husbands tend to experience more severe feelings of depression in dealing with their situation, because they do not engage in risky behavior but have to experience the positive impact of HIV (Riasnugrahaini, 2011).

Riasnugrahaini (2011) explained that a wife who was infected with HIV/AIDS from her husband as an injustice because she was infected even though she had never done any risky behavior. Injustice has an impact on various feelings such as sadness, anger, confusion, and denying the truth, shame,

guilt for having the wrong partner, even anger towards God, and the most significant feelings are anger and hatred for having to live an unfair life, negative feelings this often results in negative behavior such as self - isolation or avoiding environment. As someone who gets the name PLWHA due to accidentally contracting it, it feels much more painful (Hidayanti, 2013). Hasanah and Sulistiadi (2019) who reviewed several studies in South Asia found that the women with HIV still felt fear to disclose their HIV infections to family members or people around them because those who revealed HIV status experienced social exclusion also had difficulty receiving medical assistance.

In some cases, housewives who are infected with HIV & AIDS also have double burdens such as caring for a sick husband, caring for children who may also be infected, earning a living because the burden of spending will be even greater (Yulianti, 2013). Sarafino and Smith (2010) state that a severe illness can cause negative feelings such as anxiety, depression, anger, or a sense of helplessness and certain negative feelings.

Anxiety can directly increase the risk of developing physical illness. Severe and chronic anxiety can produce changes in physiological function that can increase the risk of disease (Zvolensky & Smits, 2007). If high anxiety occurs in PLWHA it can jeopardize their disease management, interfering with their adherence to anti-HIV treatment (Zvolensky & Smits, 2007).

Based on these problems, a research question was formulated in this study; what is the picture of anxiety in housewives infected with HIV/AIDS and what are the factors that influence it?

Method

This study used a qualitative method with a case study investigation strategy. Qualitative research intends to understand phenomena about what is experienced by research subjects such as behavior, perception, motivation and action holistically, and by describing through words and language in specific natural contexts and using various natural methods (Moleong, 2007). Case studies are part of qualitative research that allows researchers to explore real life both a case and various cases in detail and more deeply by collecting through various sources of information (Creswell, 2018),.

The research sample was determined through criterion sampling, a technique for determining samples taken based on several criteria to ensure data quality (Sugiyono, 2017). The criteria for the subjects in this study were women who had been married and were infected with HIV as evidenced by a doctor's diagnosis. The study involved two housewives, called S, 40 years old and KL, 36 years old, previously married and infected with HIV/AIDS from their partners. both subjects were private employees who quit their jobs because they are infected with HIV. When the research was carried out, both of them worked as mentors for PLWHA

The data were obtained through semi-structured interviews, a kind of interviewing technique that is done by the researcher first asking questions that have been structured then it is deepened to extract further information in depth about the research topic that we wants to study (Arikunto, in Duli, 2019). The reliability of the data is revealed through (1) member check, a process of checking the data obtained by the researcher to the data provider to reveal how far the data obtained is in accordance with that given by the data provider (Sugiyono, 2012). (2) Triangulation, a technical method of checking data validity that utilizes another data for checking purposes or as a comparison to the data obtained (Moelong, 2007). In this study, it was carried out by involving significant others, the subject's friends who worked together as peer supporter.

Results

Anxiety on subject S

Subject S' husband is often a fairy to another city to work. S knew her husband used to go to nightclubs and had a risky sex life but S can't stop it. S had a child who died at the age of 2 because was infected with HIV, but S only realized it when S himself was infected with HIV/AIDS. S' anxiety

started when her health condition deteriorated, thus she had to repeated examinations at the hospital until she was hospitalized. Subject S actually felt angry at her husband and did not accept her illness but at that time the subject could not express feelings of anger at all because the subject's physical condition was too weak. S called her husband who was in another city to tell about her condition and her husband felt sorry but at that time her husband had also been diagnosed with HIV/AIDS in a more serious condition and he died immediately without them having a chance to see each other.

After being diagnosed with HIV infection, the subject's first response was shock, denying the results of the VCT, anger, feeling weak and the subject at that time thought she would die soon, confused, shock, negative thoughts about death. S' health condition would then worsen and thus, receiving additional diagnosis of Tuberculosis with treatment side effects such as nausea and vomiting. Additionally, dizziness, chill, and thoughts of death were becoming more frequent.

Subject S not only faced thoughts and worries about death, but also about the stigma that would be received from her family and environment, thus she hid her illness and was forced to bear her suffering alone. sometimes the subject accidentally meets an acquaintance at the hospital, the subject lies to hide the purpose of going there for fear of being known as PLWHA's status, a fear associated with the possibility of stigma.

Subject S began to feel less anxious when she met people with the same illness in the hospital and received peer support from the Victory Plus Foundation which provided emotional support and information about the ARV treatment process which decreased over time. Knowing other PLWHA at the Victory foundation made her feel supported, secure, and like she had friends to share stories with. S became more open mind and optimistic that her treatment would be successful. thoughts of death began to diminish and eventually disappear.

Since she was very young, S was taught by her parents to be independent and S was also well educated. The previous personality factors influenced the subject's ability to overcome her anxiety. once S was able to control her negative thoughts, S was able to face her illness steadfastly, . and took positive lessons from her experience as a PLWHA and decided to work as a peer supporter for PLWHA.

Anxiety on subject KL

Subject KL used to be a housewife with 2 twin sons. Before marriage, her husband was a drug addict. KL initially experienced anxiety due to the deteriorating health condition of her husband and children. They had repeated diseases and the doctor advised KL's husband to take a VCT test, in which the results showed he was diagnosed with HIV. KL was very shocked, sad, and cried a lot. The doctor also suggested KL and her two children to also be tested for VCT, which turns out to be positive for HIV infection for all three of them.

KL felt very shock, grieving, and felt guilty for transmitting HIV to her two sons, followed with having negative thoughts about death. KL's husband was immediately hospitalized while KL and her two sons started on ARV treatment. KL experienced severe side effects from ARV treatment such as hallucinations, hearing suicidal calls, vomiting, weakness, gloomy, sleeping difficulties, and loss of appetite. KL also lost the will to live, but at the time, she still has to take care of her husband and two children

The condition made KL to become even more depressed and anxious, which caused other negative thoughts to appear like a cycle. KL thought what if her children's condition worsened? these sentiments reinforced the existing thoughts of death which consequently made KL even more afraid of losing her kids to the point where it dominated her thoughts, resulting in panic attack, lost of self control, and explosive tantrum at her son. KL has a long history of anxiety; she grew up as a timid child who gets angry easily whenever things did not go according to her expectations and had a fear of death for a long time.

KL's condition worsened by the fact that the people around him don't support him at all. She was treated differently by her brother-in-law and received improper treatment from medical

personnel at the hospital which made her felt worthless and discouraged. The bad treatment she received made KL afraid to tell her own parents about her condition because she was worried about getting the same treatment.

KL decided to have online counseling with an ustadz, who then helped her open up her condition to her parents. After her husband's passing, KL returned to her parents' house, but soon gave up on the ARV treatment, which unfortunately followed by the passing of one of her sons because he didn't get the aforementioned medical treatment. KL felt burdened with guilt over the death of her son and worries excessively about losing another son at the same time. The support from the ustadz made KL had the courage to attempt ARV treatment again, but the same aftermath occurred; she experienced severe side effects such as nightmare that made her even more anxious, to which she associates it with death, stigma, discrimination, which thereby reinforcing her fear of losing her son, then she had panic symptoms and become irritable. As a result, she gave up on the treatment once again, until the PLWHA peer supporter helped her to get medication with a lighter dose. Although the ARV effect was reduced, KL kept being anxious about her child's physical condition.

After her physical condition got better, KL joined as a peer mentor for PLWHA despite of her increasing anxiety since then; as a peer supporter, she frequently in contact with PLWHA patients whose condition worsened, to which KL assumed that a similar condition could occur to her and her son. Such negative thought made her pessimistic about her own health, becoming distrustful, and did not want to make any plans for the future. Whenever she thought about her illness, she lost her appetite, felt weak, having sleep difficulties, and felt dizzy.

Although the anxiety which came from stigma and discrimination affects KL's social life and led her to close herself off from her environment, KL is still receiving peer supports, which motivated her to start opening up to her close friends about her health condition.

Discussion

The results shows that the two subjects, S and KL, began to show anxiety since their health conditions—along with their families—began to decline. Anxiety gets stronger when it was confirmed that the husband got infected with HIV/AIDS, which results in subject 1 to not only worried about her own condition but also about the condition of her partner. Moreover, subject 2 was also worried about her children, thinks about death, and is afraid of losing her family members. These results are in accordance with the opinion of Christ, Rhudick, and Dibner (Yuliana, 2015) which states that individuals who experience high death anxiety are influenced by problems in poor physical and emotional health.

The two subjects experienced a very strong emotional response when they found out they were infected with HIV. They cried, showed deep sorrow, confusion, depressed, and denying the test results and also includes blaming herself for transmitting the disease to her children. This finding is in accordance with what Djoerban (Sudoyo, et al. 2006) mentioned that after being diagnosed with HIV, most people tend to show strong reactions such as refusing test results, crying, regretting, scolding themselves, and even isolating themselves when diagnosed with HIV.

Both subjects experienced symptoms that are commonly found in HIV-infected patients, pneumonia, fungal infection in the mouth, drastic weight loss, etc. This condition causes anxiety in S and KL who start to think and fear death. Anxiety gets stronger when the side effects of ARV treatment are overwhelming, such as hallucinations of hearing suicidal calls, vomiting, weakness, loss of happiness, sleeping difficulties, loss of appetite, thoughts of death, etc. These side effects were alarmingly severe that the subjects lost their enthusiasm for living their lives. This finding is supported by Satiadarma and Zamarlita (2008) that anxiety about death appears in patients with chronic diseases along with the weakening of the physical, social, and psychological conditions of sufferers.

Research found that the two subjects shared many common experiences but also differ in certain respects. After subject KL lost her husband and her child, she had a negative view of the future.

KL showed poor adherence to treatment thus her health improvement was less stable. KL continue to worry about her health & her son's. KL lost interest in planning for the future, she wanted to avoid thinking about her future which was considered too scary. this finding is in line with the statement by Chusna and Nurhalina (2019), which says that sufferers perceive the future as futile and do not give the slightest hope. will always think until here but always sustainable.

Both subjects responded to various HIV-related illnesses and ARV treatment in different ways. Subject S was very strong and determined to go through the treatment and felt optimistic after meeting other people with the same illness in hospital and getting help from peer supporter, while the subject KL showed an unstable condition as she dropped out of ARV treatment twice despite receiving the same social support as S.

Subject S and KL had different mental conditions before being infected with HIV. S was a strong person and accustomed to being independent since young, while XL is an anxious person since young; she would feel such way when things are not as she expected and she has a fear of death. The findings of this study illustrate what Duko, Toma, Asnake and Abraham (2018) stated that patients with a previous history of mental problems are more prone to experiencing anxiety, apart from the fact that HIV itself causes extreme symptoms.

Different responses of the subjects lead to different developments. After receiving treatment and social support, subject S became calmer, her anxiety decreased and she was able to take lessons from her experience and then focused on her work as a peer supporter for PLWHA. As for KL, she is still grappling with her unstable health and anxiety—although subject KL also works as a peer supporter, but whenever she confronted to PLWHA whose health was deteriorating, KL become even more anxious due to the arising bad thoughts of the condition that could happen to her and her only child.

In addition to painful symptoms and treatment, the fear of stigma was another source of anxiety for the subjects. Both subjects tried to hide their illness from the environment, even to their own parents. They are very afraid of being stigmatized by their surrounding environment. Subject S had to lie to her acquaintances when she met at the hospital. The subject of KL experienced the direct effects of the stigma on PLWHA, she was badly treated by her in-laws' family and the medical staff at the hospital hence she closed herself more—even when experiencing the side effects of ARV, she decided to stop treatment without doing consultation with any medical personnel.

Both subjects' experience supported by Esplen's research (2007) that housewives with HIV/AIDS are vulnerable to stigma and discrimination, as well as rejection from the family, especially the husband's family. This results in housewives with HIV/AIDS not accessing existing health services, because there are thoughts of being abandoned, not being considered, and becoming a burden to the family.

Bhiwara (2016) mentioned that the stigma and discrimination against PLWHA, have contributed to the emergence of negative thoughts related to the illness, which includes undeserving to be accepted or loved by others. Other anxiety symptoms include the subject to feel that their life is meaningless, the future is bleak, and helpless because the illness will cause death. The existence of these thoughts and feelings makes PLWHA tends to become angry, helpless, stressed, and depressed.

Both subjects S and KL experienced that to admit being PLWHA is something scary because it is identical to the stigma attached to it. The findings in both subjects are consistent with the findings of Hasanah & Sulistiadi (2019) that in South Asia many HIV-infected wives do not dare to show their status as HIV-infected people because of discrimination and blame by family members and the people around them. and It also makes difficult for them to get social or medical assistance. . The fear of being treated differently makes it difficult for PLWHA to relate to others and are afraid to share their experiences, even to declare themselves sick. On the other hand, the support or elimination of stigma from people around PLWHA will also have an impact on increasing the utilization of health services (Shaluhayah, Musthofa, Widjanarko, 2015).

As a housewife, the subject of KL was not only worried about herself, but also worried about her entire family. She was worried about her husband and one of the sons before they died and worried about the other child because he was also infected with HIV and his condition was significantly different from other children in general. KL's anxiety makes her to feel hopeless and does not want to think about the future. These findings are supported by Ernawati, Rahayu and Kurniawan (2019) who found that the fear of self-stigma and children is something that is felt by housewives with HIV/AIDS; they are afraid to reveal their disease status to their families and communities around them. They think their status will cause their children to experience stigma or discrimination.

However, based on the findings of this research, Subjects' disclosure of their status in PLWA could have impacts on the social support received by the two subjects; from family, friends, and peer support groups. Peer support groups in addition to providing social support are also a source of information for PLWHA. Herbawani and Erwandi (2019) stated that knowledge of HIV status is considered very important because knowledge is the main gate to access prevention of transmission and treatment of HIV/AIDS. Another study conducted by Campbell, Mamame, Nair, and Sybia (2005) said that the lack of information or misinformation or confusing information can lead to a negative response for PLWHA. This is reinforced by a report from Khamarko and Myers (2013) which states that social support, including information support, will have a good impact on PLWHA and their families. Previous research by Demirel, et al (2017) showed that disclosing HIV status to family, friends, or health professionals can be a process of social stigma that results in fear of rejection, isolation, or exclusion.

Conclusion

Studies on both subjects shows several important points to note despite the differing dynamics: (1) Social support can be used as an important point in overcoming both anxiety because of the effects of disease due to HIV infection, medication, and anxiety due to stigma. (2) Both subjects S and KL have different progress; KL develops more slowly but consistent social support finally makes KL dare to open up about her status. (3) Psychological conditions before and after HIV infection are important factors to consider integrated interventions. (4) Subjects S and KL live in cities which are quite large but lacks sufficient information about HIV/AIDS despite that knowledge is useful for the prevention and treatment of HIV/AIDS as well as prevention of stigma in PLWHA. (5) This research was conducted in urban areas that have complete health facilities and support, so it is recommended that further research be carried out in areas with different conditions.

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