



## Lived Spiritual Experiences of Patients with HIV/AIDS: A Phenomenological Study at Waluyo Jati Hospital

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### ABSTRACT

**Introduction:** The issues faced by HIV/AIDS patients are not only psychological but also spiritual, such as their relationship with others, themselves, and God. The negative labels received by HIV/AIDS patients can sometimes lead them to blame God for the trials they face, as each individual has different levels of spirituality. **Objectives:** The purpose of this research is to understand the spiritual experiences of HIV/AIDS clients at Waluyo Jati Regional Hospital, Kraksaan Probolinggo. **Methods:** This study employs a qualitative research method with a phenomenological approach, using data collection techniques such as observation, interviews, and documentation. The number of informants in this study is five people, who have reached saturation. **Results:** The results of the study show that the spiritual experiences of HIV/AIDS clients involve drawing closer to God by praying and spending their free time reciting the Quran. However, in their relationships with others, HIV/AIDS clients keep their illness a secret because they fear being shunned by those around them, and they even hide it from their families. **Conclusions:** Therefore, further research is needed to address the social issues faced by HIV/AIDS patients.

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### A. Introduction

HIV/AIDS is considered one of the most dangerous chronic diseases in today's era. Currently, there is no country on Earth that claims to be free from the severity of HIV/AIDS (Irawati, 2011). This is due to the virus attacking the human immune system for five to ten years or more, which makes the body susceptible to other diseases (Murni, 2016). HIV/AIDS poses a serious threat to society (Armiyati, Rahayu, & Aisah, 2015).

The impact of HIV/AIDS extends beyond biological effects to psychological, social, cultural, economic, legal, and educational consequences (Putra, 2016). HIV/AIDS patients often face unfair treatment and discrimination, not only from their families and the community but also from healthcare staff who may refuse to provide medical services (Ardhiyanti, 2015). They are sometimes told that HIV is a punishment for their sins (Udji, 2015).

According to WHO, since the beginning of the epidemic, more than 70 million people have been infected with HIV, and approximately 35 million have died from HIV-related causes (WHO, 2016). Globally, about 36.7 million people were living with HIV by the end of 2016. It is estimated that approximately 0.8% [0.7-0.9%] of adults aged 15-49 worldwide are living with HIV (WHO, 2016). In Indonesia, between January and March 2017, there were 10,376 reported cases of HIV and 673 cases of AIDS. The highest percentage of HIV infections was reported in the 25-49 age group (69.6%) and AIDS in the 30-39 age group (38.6%), with a male-to-female ratio of 2:1 (Ministry of Health & Data, 2013).

East Java ranks second in Indonesia for the highest number of cases from 1987-2014, with a total of 8,976 HIV/AIDS patients, which is not an achievement to be proud of (HIV/AIDS, 2014). In Probolinggo Regency, there were 240 reported HIV cases in 2014 from 33 health centers, with 179 cases diagnosed as AIDS, the highest being in the Paiton health center area with 110 cases (Probolinggo Health Office, 2014).

Spirituality plays a crucial role in the treatment of HIV/AIDS (Collein, 2010). Research by Leane Zilar using a quantitative method documented that spirituality is very important for the lives of HIV/AIDS clients (Zilar, 2002). The significance of spirituality is also supported by research from Heidemarie Kremer, who states that spirituality can act as either a barrier or a motivator for HIV/AIDS clients in their ARV treatment (Kremer, 2009). One example of a spiritual issue experienced by HIV/AIDS clients is the tendency to blame God for their suffering upon diagnosis, which can lead to disruptions in worship, diminished faith, and spiritual distress. Qualitative studies indicate that clients with HIV/AIDS may experience negative effects on their spirituality upon learning of their diagnosis (Armiyati et al., 2015).

Based on the phenomena described in previous research, which highlights the lack of understanding among HIV/AIDS clients and the community about transmission and causes of the disease, there is a tendency for clients to become isolated, leading to stigmatization, blaming God, and reluctance to engage in religious practices, resulting in a perceived loss of purpose in life. This results in decreased faith in God. Qualitative research in Indonesia has not yet been published on the spiritual experiences of HIV/AIDS clients, although quantitative studies have been conducted (I Gede Meyantara Eka Superketria). Therefore, the researcher aims to conduct a qualitative study to explore the spiritual experiences of HIV/AIDS patients more deeply, offering various solutions to better understand human life in its social reality through a phenomenological approach (Afiyanti, 2014).

## **B. Methods**

This study uses a qualitative method with a phenomenological approach. The qualitative approach is employed to obtain comprehensive and in-depth information about the experiences of HIV/AIDS patients undergoing treatment at the VCT clinic of Waluyo Jati Hospital in Kraksaan, Probolinggo. This approach also provides participants the opportunity to share their stories and spiritual experiences during therapy from an individual perspective. A total of 5 participants were selected until saturation was reached.

Participants were chosen based on criteria set by the researcher. The researcher was assisted by the Head of the VCT Clinic as a source of information in selecting participants. The Head of the Clinic helped provide the names of potential participants and facilitated their introduction

to the researcher. Following this, the researcher approached the participants and established a close relationship to gain their trust, encouraging them to provide information and share their experiences.

To ensure data validity, the researcher conducted observations, in-depth interviews, and cross-checked documents. The selective or highlighting approach was used in data analysis.

### **C. Results and Discussion**

Based on the transcript from the interviews and field notes made by the researcher, a simultaneous analysis was conducted. This resulted in the identification of four themes: (1) the relationship of HIV/AIDS clients with themselves; (2) the relationship of HIV/AIDS clients with others; (3) the relationship of HIV/AIDS clients with God; and (4) the future hopes of HIV/AIDS clients regarding their illness.

#### **1. Self-Relationship in HIV/AIDS Clients**

In this study, it was found that the response of acceptance or rejection of the illness experienced by HIV/AIDS clients is a natural phenomenon. Both positive and negative attitudes serve to protect oneself and others from HIV (Ardhiyanti, 2015). Before accepting their condition, participants initially expressed feelings of denial, shock, and rejection, which aligns with the findings of Reni Prima Gusti & Mutia (2015). The researcher believes that such denial is a normal reaction, as participants may feel ashamed of having a stigmatized disease. This is also noted in the book "Asuhan Keperawatan pada Klien HIV/AIDS" by Dr. Nursalam.

According to the research, feelings of denial were experienced by participants upon being diagnosed with HIV/AIDS, leading to self-rejection and a lack of self-confidence. The researcher suggests that this denial may be due to some participants perceiving themselves as mere objects or victims of transmission from their partners. This is consistent with the study by Armiyati, Rahayu, & Aisah (2015). The theory explains that denial and lack of self-confidence can hinder everything, potentially leading to suicidal thoughts (Cahyadi, 2000 & Djorban, 2014).

The research results indicate that nearly all participants expressed shock upon learning of their HIV-positive diagnosis, which is consistent with the findings of Fauziyah & Zahroh (2018). The researcher argues that the shock experienced by some participants reflects their unpreparedness for the disease, especially since some were not the primary transmitters but rather partners who were unaware of their partner's HIV status. The following is a statement from the fourth participant: "iy ...drop pengen mati saya kan sebenarnya saya gak drop yana gak sakit Cuma bapak yang sakit tapi saya cek darah positif kaget sekali saya" This also occurs because informants feel unprepared and lack confidence in their ability to contract HIV/AIDS (Fauziyah & Zahroh, 2018).

Based on the research findings, after receiving input or support from close individuals, the participants felt more accepting of their condition. They felt resigned, viewing it as a test from God. The researcher believes that as a person draws closer to God, their heart becomes more open to patience and acceptance. This sentiment is reflected in the statement made by the third participant "menerima saya, memang itu termsuk ujian dari Allah" This is consistent with the findings of Reni Prima Gusti and Mutia (2015), and aligns with the theory proposed by Kubler-Ross (1947) as cited in Nursalam (2007). According to this theory, over time, patients begin to adapt, their painful anguish diminishes, and they

move towards identifying themselves as someone with limitations due to their illness and as a person who has accepted their condition.

Positive attitudes identified in this study include the willingness or effort to take medication and the attempt to be grateful. The researcher argues that the greater a person's effort and determination in life, the stronger their physical resilience will be. With strong motivation, participants are less likely to miss taking their medication or attending follow-up appointments at the hospital. Efforts to adhere to medication regimens and engage in activities are consistent with the findings of Reni Prima Gusti and Mutia (2015). According to modern medical guidelines, it is essential for individuals to undergo comprehensive health checks. The efforts of medical professionals to save the lives of patients are crucial, as they enable optimal treatment (Thawil, 2007).

In the study, not only positive attitudes but also negative attitudes were observed among participants, such as feelings of shame, self-isolation, and worry. This is consistent with findings from Armiyati et al. (2015), which revealed that participants initially experienced a range of emotions including shock, fear, anger, frustration, shame, sadness, and disbelief.

Based on the research, after being diagnosed with HIV, participants felt ashamed and kept their condition secret. The researcher posits that the shame experienced by participants stems from their inability to accept the diagnosis and their fear of the disease, which they perceive as a divine curse. They often believe that HIV is a consequence of immoral behavior, such as infidelity or prostitution. This finding aligns with Armiyati et al. (2015), which suggests that such experiences evoke various feelings and stress reactions, including frustration, anxiety, anger, denial, and shame (Nursalam, 2007).

The study also found that after being diagnosed, participants tended to withdraw or isolate themselves from society and their surroundings. The researcher argues that this self-isolation is a protective mechanism against potential ridicule from others due to their shame and desire for solitude. This is consistent with Fauziyah and Zahroh's (2018) research. Whether consciously or unconsciously, individuals in this stage may reject all facts, a response also noted by Reni Prima Gusti and Mutia (2015). Theoretical perspectives suggest that such isolation or withdrawal can lead to feelings of worthlessness and depressive symptoms (Nursalam, 2007).

Additionally, the research found that participants felt anxious about various concerns, such as fear of being ridiculed, concerns about a short life expectancy, and general anxiety about their condition becoming widely known. The researcher believes that these worries are natural, as participants often focus solely on death, which leads to fears about not living long enough to see future generations, as expressed by participant four, "ingin ngelihat cucu saya masihh kecill-kecil dok, khawatir tak kacapok dok, jadi saya rutin minum obat gak pernah telat rutin" This finding is consistent with the research by Irawati (2011). The theory also explains that concerns are typically experienced by HIV/AIDS clients due to discomfort in receiving care before an HIV test, or because they have undergone an HIV test but are hesitant to retrieve the positive results, fearing that there may be no further resolution to the outcome (Udji, 2015).

## **2. Relationship of HIV/AIDS Clients with Others**

Based on the research findings regarding the theme of the relationship between HIV clients and others, such as sharing time, support, and the knowledge of family members (e.g.,

living with family and caregiving), these results align with the research by Sandy Marubenny (2013). According to this study, family or neighbors often cannot resolve their problems alone and require the assistance of others. The findings indicate that social support is a crucial mediator in addressing personal issues. This is because individuals are part of a family (Nursalam, 2007). A family consists of two or more people living together with emotional and regulatory bonds, and each individual has a specific role within the family. The family is an integral part of human life, interacting with individuals daily (Suprajitno, 2014).

Neighbors or the act of being a good neighbor is a fundamental aspect of human social existence. The quality of human life and community well-being is significantly influenced by how we build relationships with our neighbors (Syafrowi, 2009). The research findings show that the need for relationships with others is also explained by the first and fourth participants, who expressed the importance of these interactions, "saya merahasiakannya dek karna saya tidak mau dijauhi, dan lagi sya masih butuh teman dan tetangga dek" It is evident that individuals inherently need and socialize with others.

The research findings reveal that HIV/AIDS clients often conceal their identity or status from others due to fears of being shunned by those close to them. The researcher argues that keeping their illness status secret from family is considered the best option by some clients, as illustrated by the second participant's statement, "saya gini dek kalau banyak yang tau nanti tambah kepikiran saya khawatir di buli keluarga saya" The research findings indicate that clients with HIV/AIDS often choose to conceal their disease status from both family and others, primarily to maintain their self-image and avoid being ostracized. This approach helps participants feel more at ease. This finding is consistent with Sony Wahyu Tri Cahyono's (2017) study, which found that most participants who learned they were HIV-positive engaged in hiding their health status as a coping mechanism (Wahyu, 2017). Theory also supports this, explaining that concerns about discriminatory treatment often lead individuals living with HIV/AIDS to hide or keep their status confidential (Leila, 2018).

Concealing one's disease status is not limited to family members but extends to others as well, to preserve the participant's self-esteem and protect their social image. According to the research, HIV/AIDS clients conceal their status to avoid being shunned or marginalized by those around them, especially close friends or neighbors. This aligns with Sinaga's (2015) findings, which highlight that the challenges faced by people with HIV/AIDS extend beyond physical deterioration to include social issues such as negative labeling and discrimination from their environment. The severity of the condition also affects the social aspects and impacts the patients' overall health (Armiyati et al., 2015).

### **3. Relationship with God in HIV/AIDS clients**

Contrary to the stigma or perceptions that view HIV/AIDS as a divine punishment or curse for immoral behavior, such beliefs are deeply entrenched in society. However, the research findings on the theme of the relationship between HIV/AIDS clients and God reveal that these clients' practices of worship contradict societal stigma. Clients with HIV/AIDS engage in prayers, such as performing Salah and participating in positive activities like reciting prayers or studying the Quran. They recognize that drawing closer to the Almighty is a positive and essential aspect of their lives.

According to the research, HIV/AIDS clients perceive their illness as a test from God designed to enhance their spiritual practice. This is consistent with Setyoadi's (2017)

findings, which suggest that spiritual changes manifest as a closer relationship with God through surrender, repentance, and diligent prayer (Setyoadi, 2017). Initially, all participants experienced denial upon learning of their HIV/AIDS diagnosis, but increased devotion helped them realize that their current situation is part of a larger, divinely orchestrated plan, as God's wisdom surpasses human understanding.

The importance of spirituality is also emphasized in theory, which suggests that patients should be facilitated to draw closer to their Creator through continuous worship, thereby achieving tranquility during illness (Nursalam, 2007). Frequent worship can lead to greater peace and acceptance of what God provides, whether it be a trial or sustenance.

From the perspective of psychoneuroimmunology (the study of the immune system from a psychological standpoint), as discussed by Professor Sholeh, the act of prostration during Salah is unique. The philosophy behind prostration involves lowering oneself to the lowest position, even below one's own buttocks. This action elevates a person to a high spiritual level. Routine prostration trains brain blood vessels to receive ample blood supply, as the heart is positioned above the head during prostration, allowing maximum blood flow to the brain. This means the brain receives an oxygen-rich blood supply that enhances cell function (Sakura, 2016).

Performing the Tahajjud prayer with sincerity, devotion, precision, and continuity is believed to foster positive perceptions and motivations, thus enhancing coping effectiveness. Positive emotional responses can help prevent stress reactions. Individuals who regularly perform Tahajjud prayer will likely adopt both strategies mentioned, as the essence of Salah is to live realistically, remain optimistic, and be prepared for life's challenges, thus maintaining a constructive attitude. Optimism helps maintain homeostasis, which is achieved through feedback mechanisms that limit excessive reactions and preserve normal conditions. Failure of these feedback mechanisms can lead to excessive stress.

#### **4. HIV/AIDS clients' hopes for their disease**

Hope is an essential positive attitude that anyone seeking progress must possess. As stated by Januar (2008), hope enables individuals to wait indefinitely as long as it remains alive in their hearts. According to the research findings on the theme of hope for HIV/AIDS clients concerning their illness, their aspirations include desires for a long life and continued health. Clients with HIV/AIDS have long-term goals such as wanting to see their grandchildren and care for their parents. They remain determined to fight their illness through various means, including regular medication and maintaining a positive outlook.

Positive thinking assists HIV/AIDS clients in combating their illness, as explained by the Positive Biological Response (BPR) theory. This theory posits that positive thinking generates biological reactions that are calming and beneficial to individual health. In such conditions, it is said that positive thinking has favorable biological effects (Yovan P. Putra, 2001). An experiment conducted in 2003 by geneticist Kazuo Murakami provided scientific evidence supporting the beneficial effects of positive thinking on human genes. His research demonstrated that genes can be switched on or off by various factors. Specifically, positive factors such as joy, trust, belief, and prayer can lead to the transcription of genes beneficial for health (Tanu, 2009).

Perceptions and beliefs received throughout life have a profound impact. Bruce Lipton, a biological scientist, argues that these factors are even more influential than our thoughts because they permeate our cells. This implies that our thoughts control our biological conditions. Psychoneuroimmunology experts show that we can alter incorrect perceptions underlying our thoughts and behaviors, which are often limiting and self-sabotaging. Fear, anger, and guilt can trigger diseases in our bodies, but releasing the past, forgiving, thinking positively, and learning to love oneself allow us to create balance and harmony, leading to a more positive future (Campbell, 2016).

The mechanisms of enhancing immune resilience through psychoneuroimmunology can be observed by linking changes in hormones and neuropeptides involving mental conditions (stress) in the body's resilience mechanisms. These mental conditions are described as emotional states reflecting mental disorders.

#### D. Conclusion

Based on the research findings, the following conclusions can be drawn:

1. **Relationship of HIV/AIDS Clients with Themselves:** Clients accept their condition and make efforts to adhere to regular treatment.
2. **Relationship of HIV/AIDS Clients with Others:** Clients are able to socialize as usual and participate in various activities held in their respective environments.
3. **Relationship of HIV/AIDS Clients with God:** Clients accept the trials given by God, and they seek to strengthen their connection with God, believing that their condition is a test from Him.
4. **Hope of HIV/AIDS Clients Regarding Their Illness:** Clients wish for a longer life and hope to continue their usual activities.

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