

# Resilience in Relation to Adherence to Antiretroviral Therapy in People Living With HIV: A Qualitative Study

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## Abstract

Antiretroviral therapy (ART) adherence significantly impacts the survival and quality of life of people living with HIV (PLWH). Despite the challenges faced by PLWH, adherence remains crucial. Thus, cultivating resilience in ART is essential for optimal treatment outcomes. This qualitative study explored the experience of resilience in relation to ART adherence among PLWH. Semi-structured interviews with 10 participants were conducted and inductively analyzed. Participants' resilience in ART adherence was reflected in their achievements related to cultivating the habit of taking medication and in their convictions that the medication was a daily necessity. PLWH developed resilience through strategies encompassing finding purpose through faith and motivation, fostering wellness by obtaining adequate information, enjoying life, managing disease therapy, and adopting a healthy lifestyle, and building connections by finding adequate support and involving in the community. Nurses are crucial in HIV management, fostering resilience for successful ART adherence and ensuring effective treatment outcomes.

## Keywords

adherence, antiretroviral therapy, HIV, resilience, Indonesia

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## Introduction

The introduction of Antiretroviral Therapy (ART) has transformed HIV infection into a manageable chronic condition through consistent medication adherence. Adherence to ART stands as a cornerstone in ensuring optimal health conditions for individuals living with HIV (PLWH), contributing significantly to enhanced survival rates and improved quality of life. Maintaining a high adherence rate of 95% or more is pivotal for successful treatment outcomes, as non-adherence correlates with virological, immunological, and clinical failures, potentially escalating the risk of resistance to first-line ART (Bezabhe et al., 2016; Kim et al., 2018).

Globally, optimal adherence to ART remains a formidable challenge, with rates fluctuating between 24.1% and 63.4%, a trend mirrored in Indonesia where reported figures range from 77% to 84.16% (Bezabhe et al., 2016; de Los Rios et al., 2020; Suryana et al., 2019; Weaver et al., 2014). Antiretroviral therapy, being a lifelong commitment, necessitates persistent adherence to maintain optimal health conditions and improve the quality of life for PLWH. This long-term treatment, however, is susceptible to challenges of non-adherence, with common reasons including feelings of depression or being

overwhelmed, attempts to forget about HIV, fatigue, work-related factors, and financial constraints (de Los Rios et al., 2020; Umar et al., 2019; Yona et al., 2023).

In addition to facing difficulties related to the chronic illness and lifelong treatment, PLWH encounter persistent challenges and vulnerabilities at individual, interpersonal, and community levels (Dulin et al., 2018). The majority of PLWH contract HIV through participation in high-risk sexual activities or substance abuse during adulthood, behaviors that are frequently stigmatized by society. Consequently, stigma, discrimination, trauma, socioeconomic adversities, and violence exacerbate the challenges experienced by PLWH following their diagnosis, leading to suboptimal health behaviors such as non-adherence to ART and the neglect of routine health control (Bantjes & Kagee, 2018; Dulin et al., 2018; Umar et al., 2019; Wen et al., 2021).

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Recognizing the multifaceted challenges faced by PLWH, interventions aimed at promoting ART adherence strive to instill consistent drug-taking behavior and foster HIV self-management. At its core, the success of these interventions hinges on PLWH cultivating resilience within the context of ART to achieve optimal treatment outcomes. Resilience, characterized as positive psychological, behavioral, and social adaptation to stressors, represents an ongoing process of coping and adaptation that demands dynamic strategies to address a range of challenges (Dulin et al., 2018; Morse et al., 2021). Higher levels of resilience are associated with reduced negative effects of HIV-related stress conditions, lower prevalence of depression, and, notably, increased adherence to ART and improved HIV viral load (Dale et al., 2014; Duthely et al., 2020; Montpetit et al., 2010; Wen et al., 2021).

Previous studies conducted in Indonesia have identified facilitators for ART adherence, including self-efficacy, knowledge, social support, and motivation (Nuraidah et al., 2022; Umar et al., 2019; Yona et al., 2023). Theoretical research has predominantly focused on intentional non-adherence as a barrier to ART adherence, but unintentional non-adherence also contributes significantly to the problem. Barriers reported in prior studies in Indonesia encompass forgetfulness, busyness, being asleep at medication time, running out of medication, medication availability far from home, boredom, adverse effects of ART, drug size, administration problems, depression, and stigma (Nuraidah et al., 2022; Nurfalah et al., 2019; Suryana et al., 2019; Umar et al., 2019; Weaver et al., 2014; Yona et al., 2023). Resilience engineering offers a novel perspective on adherence, focusing on the positive aspects of resilient systems. This approach emphasizes how systems anticipate, monitor, respond, and learn to avoid and recover from errors, maintaining successful performance (Furniss et al., 2014). From this perspective, resilience strategies, such as creating cues to remember tasks, organizing similar objects and tasks to reduce confusion, and checking resources before taking action, play a pivotal role in enhancing adherence and minimizing unintentional non-adherence.

The theoretical framework guiding this study is based on the resilience theory developed by De Santis et al. (2013) known as the Motivation, Management, and Mastery (MMM) Theory, in the context of HIV infection. This theory takes a comprehensive approach, extending beyond individual-level factors to acknowledge the significance of extrinsic resilient resources at interpersonal and community levels in fostering positive adaptation to adversity among PLWH. As HIV is a chronic disease entangled with social factors, this theory recognizes the dynamic nature of resilience and its role in disease management over time.

This study aims to contribute to the existing body of knowledge by focusing on the intersection of resilience and ART adherence in the Indonesian context. While previous studies have identified facilitators and barriers, the specific

role of resilience and its dynamic interplay with adherence remains an understudied area. By exploring how resilience factors contribute to ART adherence among PLWH in Indonesia, this research addresses a crucial gap, offering insights into the nuanced relationship between resilience and treatment adherence from the perspective of the participants. This approach aligns with De Santis et al. (2013) broader conceptualization of resilience, emphasizing both intrinsic and extrinsic sources and the potential for growth over time.

Drawing on De Santis et al. (2013) theory of resilience, the present study employs a qualitative methodology to delve into the intricacies of resilience in relation to ART adherence from the viewpoint of participants. By emphasizing both intrinsic and extrinsic sources of resilience, as well as the potential for growth over time, this research seeks to contribute to a more comprehensive understanding of how resilience impacts adherence to antiretroviral therapy and overall well-being within the unique circumstances faced by PLWH in Indonesia.

## Method

### Study Design

The study was conducted using a qualitative description research approach. Qualitative descriptive research studies are endeavors that seek to uncover and comprehend phenomena, processes, or the viewpoints and worldview of the individuals engaged in the study (Bradshaw et al., 2017). The study aimed to explore the experiences and perceptions of resilience in relation to ART adherence among people living with HIV/AIDS (PLWH). The research was carried out in Indonesia, specifically in the city of Surabaya, East Java and the district of Depok, West Java. This location was chosen because these two provinces are the provinces with the highest number of HIV cases in Indonesia.

### Participant Selection

A purposive sampling strategy was employed to select participants who met specific criteria. Potential participants were recruited from a non-government organization (NGO) in Surabaya and the AIDS commission in Depok. Inclusion criteria encompassed individuals aged 18 years or older, with a diagnosis of HIV/AIDS, and a minimum ART duration of 1 month. Exclusion criteria involved individuals who were unable to provide informed consent or had severe cognitive impairments that hindered participation. The selection process involved the assistance of key individuals (the steering committee of the HIV NGO and AIDS commission) who had close connections with PLWH, facilitating the recruitment of actively adherent individuals. These key individuals conveyed information about the research to PLWH in their communities. Subsequently, researchers contacted potential participants, explained information and procedures related to

the study, and if the informant agreed to participate, they were asked to sign an informed consent and make a time commitment for the interview. A total of 10 PLWH participated in this study. None of the individuals contacted about the study refused to participate. Qualitative research does not adhere to predefined criteria or numerical standards for sample size. Instead, the determination of the sample size is based on ensuring data adequacy, aligning with the study's objectives and achieving a high level of confidence in the research outcomes (Bengtsson, 2016; Thorne, 2020).

### *Ethical Consideration*

Ethical approval was obtained from the Institutional Review Board (IRB) at the Faculty of Nursing, Universitas Indonesia (Number: KET-234/UN2.F12.D1.2.1/PPM.00.02/2022) before data collection commenced. All research activities were conducted in accordance with ethical guidelines to protect the rights and well-being of the participants.

### *Data Collection*

In-depth interviews were conducted in accordance with interview guidelines that were tailored to explore participants' experiences with resilience in relation to ART adherence. Drawing inspiration from De Santis et al. (2013) theory of resilience, which provides a grounded framework for understanding how resilience unfolds in the context of HIV infection, the first author conducted the interviews in the Indonesian language. Sample questions used during interviews included inquiries about specific instances where participants felt resilient in the face of HIV-related challenges, the role of support systems in bolstering resilience, and strategies employed to maintain adherence in various circumstances. These questions aimed to elicit rich narratives aligning with the core tenets of the resilience theory in the HIV context.

Prior to each interview session, participants were provided with a comprehensive explanation of the study's objectives and the interview process. They were assured that their participation carried no direct benefits and that they retained the right to withdraw at any point during the interview without facing any consequences. Participants were furnished with copies of the consent form and given the opportunity to express their consent both verbally and in writing. Moreover, participants were encouraged to seek clarification and pose any questions they had about the research. All interviews, conducted face-to-face in private rooms to foster an environment conducive to open sharing, were audio-recorded and lasted approximately 20 to 45 min, ensuring comprehensive data capture. However, due to geographical distances, three interviews were conducted online. The data collection period spanned from July to September 2022.

To complement the data collection process, field notes were taken to capture contextual information. To maintain

participant confidentiality, a unique identification number was assigned to each participant, and consent forms were securely stored separately from audiotapes and interview transcripts in a locked office. Upon completion of their respective interview sessions, participants were compensated with USD 6.5 as a token of appreciation for their time and contributions to the study.

### *Data Analysis*

Data analysis was conducted using a qualitative content analysis method, to analyze the data obtained through interviews. Qualitative content analysis presents data in words and themes, enabling the derivation of interpretations from the results (Bengtsson, 2016; Sandelowski, 2010). Data analysis was done manually. Hired transcribers transcribed the recordings verbatim, and researchers subsequently cross-checked the transcriptions to ensure accuracy. Transcribed interviews were thoroughly reviewed and analyzed by the first author using inductive approach. In the initial phase of analysis, the researcher thoroughly read the transcriptions multiple times to gain familiarity with the data. Subsequently, an open coding approach was employed to identify statements directly pertinent to experiences of resilience concerning ART adherence. The researcher then created meaning units, with each unit being labeled with a specific code. Following the identification of meaning units, the researcher ensured that all aspects of the content aligned with the study's aim. Unnecessary information unrelated to the study's aim was omitted, and extended meaning units were condensed and organized into themes and categories. To uphold the quality and trustworthiness of the analysis, each stage was repeated several times (Bengtsson, 2016). The themes constructed through this analysis were considered in relation to De Santis et al. (2013) theory of resilience, which informed the data collection process. Throughout the analysis, the researcher examined how participants' narratives aligned with the key tenets of the resilience theory, shedding light on the dynamic interplay between resilience and ART adherence.

Ensuring the validity of qualitative findings is of paramount importance in maintaining trustworthiness of the research. In this study, peer debriefing sessions were conducted. Peer review/debriefing was conducted by two experts in the field, specializing in HIV nursing care and qualitative research (second and third authors), both of whom were not involved in the initial data collection. The code book, initially formulated by the primary author reviewed by the second and third authors. Any disparities in interpretation were systematically addressed through group discussion, persisting until a consensus was reached. The final codes were refined by the primary author with substantial input and contributions from all authors. The ultimate version of the code book encompassed pertinent content and illustrative quotes. Additionally, prolonged engagement with the participants

**Table 1.** Characteristics of Participants (N= 10).

Characteristics	Frequency
Age	
18–25	0
26–35	5
36–45	5
Sex	
Male	6
Female	4
Education	
Low	2
Intermediate	5
High	3
Employment status	
Working	5
Not working	5
Marital status	
Not married	3
Married	2
Divorced/Widowed	5
ART duration	
Less than 1 year	1
1–5 years	4
More than 5 years	5

and data collection process provided a comprehensive understanding of the research context and enriched the analysis.

## Results

The demographic characteristics of the participants are presented in Table 1.

All the participants were of a working age between 26 and 45 years, with the majority being male. Half of the participants were divorced or widowed and had been taking ART for more than 5 years. In addition to participating in the interviews, participants revealed that their risk factors that caused HIV included use of injected drugs, engaging in free sex, and being infected by partners (husbands). Based on the results of in-depth interviews with research participants, this study explores the experience of resilience in relation to ART adherence among PLWH. Based on the narratives of the participants, several themes were obtained, which are demonstration of resilience related to antiretroviral therapy adherence and resilience building strategies in relation to adherence to antiretroviral therapy (finding purpose, fostering wellness and building connection) (Table 2).

### Demonstrations of Resilience Related to ART Adherence

Participants in this study demonstrated resilience through their notable achievements in cultivating the “habit” of

consistently taking their medication. This accomplishment was strongly tied to their unwavering conviction that the medication was an absolute daily necessity, an essential aspect of their lives that could not be abandoned under any circumstance. As one male participant, who had been diligently adhering to ART for 4 years, eloquently expressed, “[taking ART] It is like it has become daily food. If you do not eat rice, for example, [it’s like your body is incomplete]” (participant 1). In Indonesian context, rice holds significant importance as a staple food, and the comparison underscores the indispensability of medication in maintaining their health and well-being.

The adherence schedule became almost second nature, seamlessly integrated into their daily routines, rendering reminder aids unnecessary. This internalization of medication-taking behavior exemplified their remarkable level of resilience in managing their HIV condition. However, achieving such a level of resilience was not without its challenges; it demanded considerable time and effort on their part. These individuals demonstrated a profound commitment to their treatment, overcoming obstacles and staying persistent in their efforts to maintain optimal adherence.

### Resilience-Building Strategies in Relation to ART Adherence

Participants reported several strategies in building their resilience behavior to support ART, adherence including finding purpose, fostering wellness and building connection.

#### Finding Purpose

*Finding Purpose Through Faith and Spirituality.* In spite of the challenges that come with living with HIV, participants found meaning and purpose in life through faith and spirituality, a significant theme. Their HIV condition spurred active engagement with spiritual beliefs and religious practices, providing both existential significance and practical guidance. Faith in a higher power offered tangible coping strategies to confront concurrent life challenges. Participants consistently emphasized their reliance on God as a central facet of resilience strategies, as seen in recurring statements

*There have been changes (due to HIV), it has brought me closer to God. Well, I think like this. . . we’re all going to die eventually, I just think like this. . . we don’t know when we’re going to die, we don’t know if it’s today or tomorrow, that’s why I’ve chosen to get closer to myself, to simply surrender (Participant 8)*

This connection with faith also stemmed from participants’ recognition that while their bodies may be vulnerable due to HIV, the ultimate fate rests in God’s hands, and mortality is a universal reality unrelated solely to the virus. This understanding fostered a deepened trust in God and an intensified spiritual bond.



**Table 2.** Participants' Explanation of Resilience in Relation to ART Adherence.

Themes	Selected Quotes
Demonstrations of resilience related to ART adherence: <i>Cultivating the "habit" of consistently taking medication as daily necessity</i>	<p>"It's like there's already its own alarm, you know, like at 8 o'clock or around that time, or you just remember, like, it already has its own alarm." (P1)</p> <p>"Yes, so (taking ART) is already a habit. If it's a habit, even if forgotten, there will be a 'oh, what's this?' . . . Yes, it's like there's still something missing. Even when sleeping, but thankfully waking up." (P6)</p> <p>"But if you're already used to it, it's like 'Oh, it's already the time,' so you quickly take it (ART)." (P3)</p>
Resilience-building strategies in relation to ART adherence	
<i>Finding purpose</i>	
<i>Finding purpose through Faith and spirituality</i>	<p>"So, even though we're like this (diagnosed with HIV), maybe this is the way for us to always live healthily, to be more mindful of Allah, for us to improve our way of life, that's it. That's just my positive self, at least for me, that's how I see it." (P2)</p> <p>"There is a change, honestly. I used to rarely pray. Since I got this disease (HIV), I became more active, like that. Even during fasting. Alhamdulillah, I can go through all of that (adhering to ART)." (P3)</p>
<i>Finding purpose through motivation</i>	<p>"Seeing my parents, like (me), still haven't achieved anything, never brought joy to my parents (laughter), so that's it, the motivation (to take ART) comes from there." (P1)</p> <p>"For me, the motivation is for the future of my child. The future of my child, for myself, and for my future spouse." (P9)</p> <p>"Yeah, so that. . . I want to see my child grow up. Until they become an adult, until they meet their life partner, like that." (P8)</p>
<i>Fostering wellness</i>	
<i>Getting adequate information</i>	<p>I'm afraid. . . I've dropped out of treatment twice. . . I've heard that TLD [Tenofovir/ Lamivudine/Dolutegravir] hasn't been replaced, it's just scary. . . I'm afraid if my immune system goes down, okay, I'm afraid of the repercussions. (Participant 4)</p> <p>"I'm also worried, oh, what if I'm late. Because, you know, I've heard that if you're not compliant, the virus will become more aggressive, and things will get worse. . ." (P6)</p>
<i>Enjoying life</i>	<p>"My motivation is just like that, already take the medicine regularly, want to live healthy for my children, that's it. Don't want to get sick anymore. . . Just that, take the medicine regularly, it's called that, enjoy, bring it with enjoyment, the important thing is I stay healthy." (P8)</p>
<i>Managing disease therapy</i>	<p>I always bring vitamins (ART) wherever I go. So, during the journey, I stop. . . sometimes buy food or drinks, and I immediately take the vitamins. I don't always have vitamins at home, you know. The thing is, sometimes in the middle of the journey, there might be unexpected situations, so I have to be prepared. I bring them everywhere, there should be a supply, you know. Usually, I have two or three pills. (P3)</p>
<i>Transforming healthy lifestyle</i>	<p>"I also pay more attention to my eating and sleeping patterns, you know, because since I got (HIV), I really take care of it. So, if it's already 9 p.m., I just go to bed, even if there are offers or something, I'm done working, basically at 9, I rest. During the day, I also take a break even if it's just a short one." (P2)</p>
<i>Building connection</i>	
<i>Finding adequate support</i>	<p>"We have friends who can understand us, like the VCT clinic, coworkers, yeah, those coworkers who are psychologists, so they provide motivation. Then, at the hospital, there are also counsellors, there's a group there, so that's where I started to bounce back, I'm not the only one who is sick. Maybe it's fate that Allah has destined it like this, but my future still exists, I haven't died, I still have to fight to live ahead." (P2)</p>
<i>Involving in community</i>	<p>"Praise be to Allah, I'm gathering, engaging with fellow activists (in the community). It turns out I understand, I know, it turns out B20 (term for HIV) isn't actually terrifying. It's just a virus attacking the body. A disease that can be transmitted but difficult to transmit. So, I'm confident that people like us, all of us with B20, can be healthy, recover, resume activities, and return to a normal, healthy life." (P4)</p>

**Finding Purpose Through Motivation.** Participants expressed that having motivation as a life purpose can build their resilience, directly enhancing treatment adherence. Motivation can originate from both internal and external sources.

Internal motivation denotes the participants' drive to adhere to ART stemming from within themselves, influenced by their personal values and goals. The participants expressed internal motivation as a desire to maintain good health,

prevent other infections, and fulfill job requirements that necessitate good health. In the words of Participant 7, “I am grateful to be like this and now I do not want to get another disease, first we really have activities that we should be healthy, the second we also have a family.”

In addition to internal source of motivation, external source of motivation was highlighted by the participants as influencing their adherence to treatment. They noted that their commitment to ART adherence was fueled by their sense of responsibility toward their families. Participants expressed a willingness to prioritize their health to ensure their parents’ happiness or to care for their children. One participant remarked, “There are still children who need us, so we have to be healthy, that’s my motivation.” (Participant 2)

Nevertheless, solely relying on external motivation for their life purpose can pose challenges in maintaining high levels of adherence. When the external source of motivation diminishes, such as in the case of losing a loved one, individuals living with HIV may face a considerable risk of discontinuing their ART. As Participant 10 expressed, “Because my mother passed away. There were 2 days when I didn’t take my medication. (now) I live alone, with just my father. If my father passes away, it means I die.” Hence, cultivating internal values related to the tasks PLWH need to undertake can enhance their overall motivation.

### Fostering Wellness

**Getting Adequate Information.** Fostering wellness by getting adequate information about the management of ART was viewed as critical to resilience with respect to medication adherence practices. Some participants reported that they remained adherent to treatment knowing that ART remains the only treatment for their HIV condition and that by taking ART, they would remain healthy by suppressing HIV virus replication, as mentioned by participant 4 “Right now, it’s only ART, ma’am, that can suppress the virus, isn’t it, ma’am, not eliminating it. . . not eliminating or healing. But it can only suppress the virus”

Education helped PLWH strengthen their knowledge regarding ART management, and understanding of the importance of taking ART at the right time and around the same time very day to avoid drug resistance. However, not all individuals living with HIV (PLWH) possessed sufficient knowledge regarding the management of ART. The narratives of the participants indicated that they maintained their daily ART regimen; however, there were still instances where participants struggled to adhere to their medication schedule. The information imparted by healthcare providers played a crucial role in aiding their comprehension and fostering consistency in their ART treatment.

*I communicated with the doctor, the doctor said, “You’re late, aren’t you?” “Yes, it’s only late once, how come it can be like*

*this, doc?” Then I was given vitamins, I forgot. . . it has been a long time. He was given the medicine and said, “You don’t have to be late, one hour or two hours or fifteen minutes, you have to be organized.” That is where I started regularly and started taking the ART (on time) (Participant 3)*

The socioeconomic disparities, cultural norms and stigma surrounding HIV/AIDS, religious practices like fasting, collectively form unique circumstances in Indonesia that could complicate the adherence to ART among people living with HIV/AIDS (PLWH), impacting their ability to consistently follow medication schedules and potentially undermining treatment effectiveness, as mentioned by participant 2 “If it’s delayed (taking ART), it might be because of fasting during Ramadan.”

PLWH who have recently initiated therapy require education because, in general, they often lack sufficient knowledge about the management of ART. This knowledge gap is influenced by the pervasive negative stigma surrounding HIV, which leads PLWH to feel ashamed about seeking treatment for their condition. For example, one participant explained, “For the new ones maybe those who need education, sometimes when they are new most of them are a bit insecure, so embarrassed to be invited like that many don’t want to join” (Participant 1).

Patients who have been on ART for a long time also still need to be educated, because ART is taken for life, PLWH often experience treatment burnout and feel they have recovered. This often leads PLWH to stop treatment. One participant stated, “Exactly, (ART education) is necessary. Because, you know, it’s not impossible for someone who has been adherent to medication for years. People who have been adherent for years may actually neglect it” (Participant 6).

**Enjoying Life.** Participants revealed that to become resilient, it involves accepting their medical condition and enjoying life without excessive worry, as they believe that stress can impact their physical condition and health outcomes. As one participant said,

*Yes, now I don’t overthink things too much, because it can also have an impact, if we have too many thoughts, like, what will happen later, what will happen later. That can have an effect, because every six months we have CD4, and that can be influenced if we’re disturbed. That’s why I just carry on enjoying it, just carry on being happy even though we have this inheritance. Just carry on being happy. (Participant 4).*

Resilience, as conveyed by participants, also stems from self-efficacy and a strong personality in facing life as individuals living with HIV. “So, for myself, life goes on, if we’re sick, we need treatment, we need to believe in living healthily, but we have to fight to be healthy, right? ‘If not us, then who?’ like that.” (Participant 2).

**Managing Disease Therapy.** Another strategy for building resilience, as shared by participants, revolves around the management of their disease in fostering their wellness. The majority of participants emphasized that managing their disease is closely tied to their commitment to adhering to ART. They expressed the importance of not forgetting to take their medication to maintain their physical well-being. Various strategies were adopted by participants to support their adherence, including setting alarms. However, using alarms or notifications as an adherence practice had limitations for some participants, particularly when they were outside their homes and not carrying a cell phone or any reminder device. As a result, carrying medication everywhere emerged as another strategy employed by participants to bolster ART compliance.

*First is the intention, everyone's intention is strong once they've made up their mind, that's for their health. So, we mustn't forget, if we forget, we have to find ways not to, whether it's setting an alarm, or whatever it takes, maybe always carrying the medication wherever we go. (Participant 2).*

Participants disclosed that the HIV condition is also susceptible to stigma, which often leads many individuals living with HIV (PLWH) to keep their HIV status undisclosed. The majority of participants lean toward scheduling their medication intake at night, mainly because they are already at home and away from others. Furthermore, taking the medication before going to bed is more convenient for them, as it helps mitigate the discomfort caused by potential side effects of the medication *"The concern is that during working hours, it can sometimes be challenging. . . we don't want to make others uncomfortable, that's why."* (Participant 3).

**Transforming Healthy Lifestyle.** HIV has been associated with risky behaviors such as people who use injected drugs and unprotected sex linked to unhealthy social circles. Participants revealed that their HIV status has prompted them to transform their lifestyles into healthier ones, encompassing dietary adjustments and adequate rest. Moreover, the scheduled consumption of ART was described by participants as a reminder for them to take breaks. This is particularly relevant since a majority of participants disclosed that they adhere to their medication regimen at night. As mentioned by participant 6

*In the past, to be honest, life was portrayed as glamorous. We ate whatever we wanted. . . Yes, for example, during holidays, we'd find time to socialize without regard for time, coming home in the middle of the night. But now, our time is limited, and taking (ART) medication serves as an actual alarm. If we're still out, it means by 9 o'clock, we should be home. It's time to rest; it has become an alarm for us.*

## Building Connection

**Finding Adequate Support.** Another resilience strategy reported by participants was finding support. The family is expected to be the primary source of support for PLWH, as they are the closest ones, as mentioned by participant 6, *"Disclosure (HIV status) is indeed crucial, especially within the family. Because if, for instance, something happens to us in the future, the family is surely the ones we rely on. So, the first thing is to inform the family."* Narratives from participants revealed that family support encompasses not only mental assistance but also financial aid that contributes to their resilience. *"But because the family knows, my husband's family knows, they give a lot of support, especially for the child in my womb, right. . . so I got financial support since I was pregnant."* (Participant 2).

However, support for some participants extends beyond their families, as some choose not to disclose their HIV status to them. Several participants stated that both family support and the HIV care community were instrumental in their treatment adherence. Families, community health workers, and peers played roles in reminding participants to take their medication according to the schedule, facilitating the medication process, educating them about ART treatment, and even providing financial assistance.

*We have a group, we have friends who are always supportive, who usually remind "let's take vitamins," reminding others, or maybe sometimes 'oh it's time to take medicine. They [the health workers] have reminded us [to take medicine]. "Why haven't you picked it up yet, what's wrong?" like that. So. . . um. . . firstly, it's nice to feel cared for. Second, sometimes we forget [to pick up medicine], right, ma'am. (Participant 4)*

**Involved in Community.** Participants revealed strategies for enhancing resilience, one of which involved becoming part of HIV community support and evolving into advocates for other PLWH. By mastering the management of various aspects of HIV infection, these participants transitioned from managing their condition to achieving mastery through advocacy and fostering positive health outcomes. This transformation allowed them to become proficient in HIV management and to pass on their expertise to others, reinforcing their own resilience, as described by Participant 3.

*I began taking ART and was immediately engaged by the outreach activities initiated by the community health worker. After about 4 or 5 months, I was already participating as a speaker. I continued to be involved, and now I'm thankful to be part of the group of community health workers, helping friends in similar situations. This is why now I motivate others; it's not just about motivating myself. I apply these principles because I'm connected with other community health workers. Sometimes, we visit the office (AIDS Commission), where we receive explanations and guidance.*

This involvement extended to active advocacy through engagement in support groups, conducting outreach, attending workshops, public speaking engagements, volunteering, and informally educating members of the community. This advocacy not only equipped others living with HIV with accurate information about HIV management and ART but also fueled the participants' motivation to enhance their own resilience, as they guided other PLWH along similar paths.

## Discussion

HIV is a chronic disease that can be managed through consistent medication adherence. While antiretroviral therapy (ART) adherence can suppress HIV/AIDS symptoms and viral replication, it is important to note that the infection itself cannot be cured. For people living with HIV (PLWH), developing resilience is crucial to navigate a world filled with challenges and transitions (Dejman et al., 2015; Dulin et al., 2018; Wen et al., 2021). These adversities persist throughout the lives of PLWH and can potentially disrupt medication adherence behavior. Therefore, fostering resilience within the context of PLWH is essential to sustain lifelong treatment practices and achieve treatment goals.

The findings of this study offer insight on the experience of resilience in the context of ART adherence among people living with HIV/AIDS (PLWH). The participants in this study showed remarkable commitment to adhering to their medication regimen, transforming the task into a daily habit closely intertwined with their sense of identity and well-being. This adherence behavior was underpinned by their belief that the medication was an essential part of their lives, much like a daily food. This perspective was expressively captured by a participant who likened taking ART to the significance of consuming staple food, illustrating the crucial role of medication in maintaining their health. The successful integration of adherence into their routines expresses to the participants' resilience in managing their HIV condition. This integration into daily life underscores the participants' resilience in managing their HIV condition over time, aligning with De Santis et al. (2013) resilience theory, emphasis on positive adaptation to adversity.

Resilience-building strategies observed in the study align with De Santis et al. (2013) theory, *Motivation, Management, and Mastery (MMM) theory*, which outlines the process of resilience in the context of HIV infection. This alignment is particularly evident in the aspects of finding purpose, fostering wellness, and building connections. Participants conveyed that the genesis of resilience involves finding purpose through faith and spirituality, along with motivation. Spiritual beliefs and practices emerged as powerful tools for navigating the challenges of living with HIV, offering both existential meaning and tangible coping mechanisms, as well as their life purpose. This finding aligns with research that highlights the role of spirituality in promoting adherence to ART and well-being among PLWH (Azia et al., 2023; Barminas &

Yohanna, 2018). Religious beliefs and practices hold immense importance in Indonesian culture. Given Indonesia's predominantly Muslim population, the practice of fasting during Ramadan can present challenges to consistent ART adherence. Healthcare providers should collaborate with religious leaders to educate PLWH about the importance of adhering to their treatment while accommodating religious obligations. The intersection of spirituality and healthcare needs highlights the importance of culturally sensitive interventions, a concept emphasized in the resilience theory.

Furthermore, the presence of motivation, both internal and external sources, emerged as a significant strategy for resilience in ART adherence. Previous qualitative study conducted in Indonesia focusing on quality of life among PLWH found that despite the disruptions in their daily lives following the HIV diagnosis and management, PLWH managed to utilize their internal assets or traits and mobilized external resources to cope with these disruptions (Fauk et al., 2023). Our study findings suggest that motivation serves as their goal to maintain good health and adhere to treatment. Internal motivation rooted in personal belief and health outcomes motivated participants to be adhere. Similarly, external motivation comes from familial responsibility highlighted the importance of maintaining health for the well-being of their loved ones. However, the study's findings also underscore the theory's recognition of the dynamic nature of resilience, as relying solely on external motivation proved inadequate, leaving participants vulnerable to discontinuing treatment. This finding aligns with previous research suggesting the importance of cultivating internal motivation for sustained adherence (Fisher et al., 2006). Hence, interventions aimed at bolstering adherence should focus on nurturing internalized values aligned with maintaining treatment, alongside providing external support.

The current study also suggests that fostering wellness by being well informed, enjoying life, managing disease therapy and engaging in a healthy lifestyle were important strategies for building resilience. This aligns with the theory in the context of managing the disease process (De Santis et al., 2013). The emphasis on adequate information, particularly from healthcare providers, aligns with De Santis et al. (2013) recognition of extrinsic resilient resources. The study highlights the role of healthcare providers, particularly nurses, in enhancing participants' understanding of the importance of strict adherence to treatment. However, the need for continuous health education, respecting cultural sensitivities, and minimizing stigma reflects the ongoing nature of resilience in the face of evolving challenges. Training for healthcare providers should include cultural competence and communication skills to create a safe and non-judgmental environment for PLWH.

Mental health problems are very common among PLWH (Bantjes & Kagee, 2018; Okonji et al., 2020). In fostering mental wellness, participants adopted strategies to minimize stress and anxiety associated with HIV and found ways to



bring enjoyment into their lives. Their ability to shift focus away from constant worry and embrace life contributed to their resilience and, in turn, strengthened their commitment to adhere to their treatment. Others have also found that mental mechanisms can positively influence PLWH outlook on life, halt self-blame, and serve as a coping mechanisms to deal with the challenging circumstances associated with HIV infection (Fauk et al., 2021).

Participants in the study highlighted the crucial role of disease management in fostering wellness as a resilience building strategy, particularly concerning adherence to ART. The commitment to managing their disease was consistently linked to their dedication to adhering to the prescribed medication. Participants emphasized the importance of not forgetting to take their medication, recognizing its direct impact on their physical well-being. Various strategies were employed by participants to support adherence, incorporating medication into their daily routines and employing reminder strategies. This finding consistent with a previous study by Musiimenta et al. (2018), which demonstrated that individuals exhibiting resilience employed adaptive coping strategies, including the use of alternative cues (e.g., alarms), seeking spiritual support, and aligning their medication time with their routine. The strategies employed by participants align with the principles of resilience engineering proposed by Furniss et al. (2014), emphasizing proactive measures to prevent unintentional non-adherence. Additionally, participants strategically timed their medication intake, often scheduling it at night to avoid stigma and enhance privacy. From the previous studies, PLWH hide their medications or miss doses to avoid suspicion about their HIV status (Holtzman et al., 2015; Molla et al., 2018; Samuel Edward et al., 2018; Weaver et al., 2014). These actions, viewed through the lens of resilience engineering, can be seen as adaptive responses to navigate and overcome societal barriers. Healthcare providers should take this into account when developing treatment plans and schedules, ensuring that they are conducive to the cultural context of PLWH.

The transformative impact of an HIV diagnosis on lifestyle choices was evident among participants. Participants revealed a conscious effort to adopt healthier lifestyles. This included dietary adjustments and prioritizing adequate rest. Sleep disturbance is a prevalent and intensively distressful symptom experienced by individuals with HIV (Chen et al., 2022; Mengistu et al., 2021). The profound impact of sleep issues, may be linked to increased rates of depression in the HIV population which potentially contributing to lower adherence to ART (Mengistu et al., 2021). The scheduled consumption of ART played a dual role in participants' lives, serving as both a therapeutic necessity and a symbolic reminder for self-care. These findings underscore the intricate interplay between disease management, medication adherence, and lifestyle adjustments. Strategies employed by participants highlight their resilience and adaptability in navigating the complexities of living with HIV.

The third process of resilience based on the MMM theory is Mastering the disease (De Santis et al., 2013). In this study, building connection by finding adequate support and involving in community emerged as a strategy for building resilience and promoting adherence to ART. The family emerged as a vital source of social support in fostering resilience among PLWH. Participants recognized the pivotal role of family support, not only in providing emotional assistance but also financial aid, underscoring its multifaceted nature. The significance of family in facilitating adherence aligns with prior research demonstrating the influence of social support networks on health behaviors (Fauk et al., 2019; Okonji et al., 2020; Rueda et al., 2006). Wen et al. (2021) suggested that a supportive and accepting environmental context helps build resilience, and resilience can reduce the negative effects of HIV-related stress, therefore social support can be an intervening factor for resilience and depression. Family dynamics are central in Indonesian society. While family support emerged as a key factor in resilience-building, some PLWH might choose not to disclose their HIV status to their families due to the fear of stigma, the results of this study are in line with previous research conducted in Indonesia (Fauk et al., 2019). Thus, the interventions that help families understand HIV, reduce stigma, and foster supportive environments is needed. Support groups that include both PLWH and their families can be effective in promoting open communication and enhancing resilience, as well as improving adherence (Okonji et al., 2020). Additionally, participants cited support from healthcare providers and peers within the HIV care community as important in reinforcing their adherence. This multi-dimensional support system serves as a powerful tool in enhancing resilience, as it addresses the multifaceted challenges faced by PLWH in adhering to ART. Finally, active engagement in advocacy activities empowered participants to not only build their resilience but also support others in the community. PLWH utilized their experiences following HIV diagnosis as a social platform to educate their families and communities about HIV prevention and to encourage wellness among other PLWH (Hill et al., 2019). De Santis et al. (2013) found that PLWH who have attained a feeling of physical and psychological wellness can continue to build resilience in the setting of HIV diseases by participating in Mastering the Disease. Advocacy for oneself and others is a facet of mastery since it involves a sense of self-efficacy.

The study's findings have important implications for nursing practice in Indonesia's HIV care context. Nurses have a crucial role in supporting PLWH to enhance resilience and ART adherence. This involves providing comprehensive patient education and culturally sensitive counseling to empower informed decision making. Recognizing cultural norms and addressing stigma is essential. Nurses should offer psychosocial support, facilitating open discussions about emotions and fears related to HIV. Acknowledging the significance of spirituality, nurses can provide religious

guidance and support. Promoting family and community involvement, tailored adherence strategies, and collaboration among healthcare professionals are key. Continuous training in HIV care ensures nurses are well-equipped to provide comprehensive, patient-centered care, fostering resilience and improving ART adherence among PLWH.

## Limitations

While this study provides valuable insights into the experience of resilience among people living with HIV/AIDS (PLWH) in Indonesia, there are limitations that should be acknowledged. The sample may not have captured all experiences regarding resilience experiences or perceptions. For example, the sample did not include young adults or individuals over 45 years of age, and this may have limited the diversity of perspectives captured in this study. Further, recruitment of participants from the different social networks and regions could have resulted in gaining broader overview of the topic being researched.

## Recommendations

In the context of ART adherence, a resilience-oriented approach aims to improve coping strategies for adherence challenges and minimize the probability of non-adherence. It involves comprehending and fortifying the resilience strategies that PLWH cultivate, determining optimal methods for disseminating these strategies, and evaluating their adoption, adaptation, and effectiveness by other PLWH in successfully adhering to their ART. Healthcare providers, especially nurses, should receive training in cultural competence and effective communication to create supportive environments for PLWH. Interventions should be tailored to the Indonesian context, considering cultural norms, religious practices, and stigma. Collaborative efforts between healthcare providers, religious leaders, and community organizations can lead to more effective interventions that promote resilience and adherence to ART among PLWH in Indonesia. Finally, interventions should encompass not only medical aspects but also address the psychosocial and emotional needs of PLWH, recognizing the holistic nature of their well-being.

## Conclusion

In conclusion, this study sheds light on the experience of resilience among people living with HIV/AIDS (PLWH) in Indonesia, particularly in relation to ART adherence. The participants' narratives showed the significance of internalizing medication-taking behavior as an essential daily practice, driven by their unwavering conviction in its necessity. The findings underscore the multifaceted nature of resilience-building strategies that PLWH employ to manage their condition and adhere to their medication regimens.

These strategies encompass finding purpose, fostering wellness and building connection.

The present study's findings offer valuable recommendations for future studies and interventions targeting ART adherence. Recognizing the multifaceted nature of resilience and adherence, interventions should prioritize culturally sensitive approaches, continuous health education, and comprehensive support systems. The study provides a foundational understanding applicable not only in Indonesia but also in diverse cultural contexts. These insights can guide the development of more effective strategies to enhance ART adherence and resilience among PLWH.

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