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Sri Yona¹** Chiyar Edison** Astuti Yuni Nursasi** and Rita Ismail

- ¹ Department of Medical Surgical Nursing, Faculty of Nursing, Universitas Indonesia, Depok, West Java, Indonesia
- ² Department of Community Nursing, Faculty of Nursing, Universitas Indonesia, Depok, West Java, Indonesia
- ³ Ministry of Health Republic of Indonesia, Poltekkes Kemenkes Jakarta III, Bekasi, West Java, Indonesia

Abstract

Background: Adherence to antiretroviral therapy (ART) continues to pose a significant challenge for people living with HIV (PLWH). Non-adherence to ART can have far-reaching implications for patient well-being, particularly in increasing the risk of opportunistic infections when medication is not taken as prescribed.

Objective: This study aimed to develop a theoretical model that explains how PLWH in Indonesia adhere to their ART regimen and the strategies they follow to maintain adherence. **Methods:** The study used a grounded theory approach. Data were collected through face-to-face in-depth interviews with 21 PLWH who had been taking ART for six months or more at a non-governmental organization (NGO) in Jakarta, Indonesia, between July 2019 and November 2019. Theoretical sampling was used, and the data analysis method of Corbin and Strauss was utilized, including open coding, axis coding, and selective coding.

Results: Three stages were identified as a process of adherence to the ART regimen: 1) initiating ART, 2) missing the connection, and 3) taking control. Self-awareness was identified as the central core theme describing the ART adherence process.

Conclusion: Having adequate self-awareness to take ART regularly is crucial to improving adherence to ART. Moreover, social support from one's spouse and family members can help patients maintain adherence. Therefore, self-awareness and support systems should be included as components in nursing interventions when starting ART therapy. In addition, nurses can help identify potential support persons and provide information related to ART therapy.

Keywords

HIV infections; antiretroviral agents; adherence; grounded theory; Indonesia; social support

*Corresponding author: Sri Yona, S.Kp., M.N., Ph.D

Department of Medical Surgical Nursing, Faculty of Nursing, Universitas Indonesia Jalan Prof. Dr. Bahder Djohan, Kampus UI Depok, West Java 16424, Indonesia

Email: sriyona@ui.ac.id

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Background

In 2021, it was estimated that approximately 38.4 million people globally were living with HIV, with 650,000 deaths attributed to HIV-related causes and 1.5 million new HIV infections (World Health Organization, 2021). In Indonesia, approximately 543,100 people were living with HIV by the end of 2022. Of these individuals, around 393,538 were aware of their HIV status, 160,249 people received therapy, and only 14% reported viral load suppression after taking ART for at least six months (Indonesian Ministry of Health, 2021).

Adherence to ART is crucial for the quality of life in people living with HIV (Surur et al., 2017; Xu et al., 2017), but ART adherence remains a significant concern in Indonesia. Dropout rates from prescribed ART in Indonesia are high, with approximately 23% of those prescribed ART dropping out (Indonesian Ministry of Health, 2019). This situation can have severe negative impacts, such as an increased risk of

opportunistic infection, drug resistance, and a poor quality of life (Weaver et al., 2014; Xu et al., 2017; Zhou et al., 2018).

Adherence to ART is essential for optimal efficacy (Centers for Disease Control and Prevention, 2021), and non-adherence can lead to a susceptibility to opportunistic infection and a higher mortality rate (Castillo-Mancilla et al., 2021; Glass et al., 2015). Non-adherence to ART can also lead to the development of resistance to ART line one, necessitating a switch to ART lines two and three (Boyd et al., 2015; Rocheleau et al., 2018), which are more expensive (Farr et al., 2016).

Several factors contribute to non-adherence to ART, such as a lack of knowledge about ART, non-disclosure of HIV status, low motivation arising from pill fatigue, forgetfulness, and worrying side effects (Martiana et al., 2019; Sefah et al., 2022; Shrestha et al., 2019). On the other hand, factors such as peer support and adequate family support can increase the level of ART adherence (Audi et al., 2021; Gabster et al., 2022; Sianturi & Dorothea, 2020). Other important factors, such as

stigma, discrimination, and food insecurity, can also influence adherence to ART (Agnes & Songwathana, 2021; Shrestha et al., 2019).

In Indonesia, several studies have examined adherence to ART among PLWH and the factors that influence compliance (Fahriati et al., 2021; Nurfalah et al., 2019; Sianturi & Dorothea, 2020). Most of these studies were quantitative and evaluated the correlation between ART adherence and knowledge, support system, and education level (Fahriati et al., 2021; Haryadi et al., 2020; Sianturi & Dorothea, 2020). Few qualitative studies have examined HIV in Indonesia, including the ART regimen (Agnes & Songwathana, 2021; Edison et al., 2021; Harison et al., 2020; Ismail et al., 2022; Mahathir et al., 2021; Nuraidah et al., 2022; Nurfalah et al., 2019). However, none of previous studies examined the process of ART adherence among PLWH.

To understand the process of adherence to ART among people living with HIV in Indonesia, a qualitative methodology in the form of grounded theory was utilized in this study. This approach is sensitive to individual decision-making and the wider social context that impacts adherence. The study aimed to develop a theoretical model explaining how people living with HIV in Indonesia adhere to their ART regimen and their strategies to maintain their adherence. This study is expected to provide the basic data needed to develop nursing intervention programs that can help people living with HIV stay adherent to their medication.

Methods

Study Design

This study utilized a grounded theory approach to identify explanatory constructs among the studied phenomena and the relationships among these constructs in order to build a substantive theory (Corbin & Strauss, 2008). The study aimed to develop a theoretical model that explains how people living with HIV in Indonesia adhere to their ART regimen. This approach provided a theoretical perspective for investigating how objects and other people are interpreted and how these processes of interpretation lead to behavior in specific situations (Glaser, 1998; Noble & Mitchell, 2016). Rich data were inductively derived from participant views, feelings, and actions related to adherence with ART. The Grounded Theory strongly emphasizes symbolic interaction, using symbols such as words, roles, and gestures to construct a reality that is seen as social interaction (Corbin & Strauss, 2008; Glaser, 2002). This approach was suitable for this study, which aimed to explore the process of adherence to ART among people living with HIV. This includes interactions among patients and their environment, such as healthcare providers, other people, and stigma.

Participants

A total of 21 volunteer participants were recruited and agreed to be interviewed. They were recruited from one of the non-governmental organizations in Jakarta in 2019, before the pandemic. Participants were recruited by posting flyers at the NGO office. The NGO staff explained the study to potential participants who met the inclusion criteria (e.g., had received ART for at least six months, were at least 17 years old, and had no cognitive disorders). Participants who met the inclusion

criteria were invited by the NGO via telephone and handdelivered letters. Interested participants then contacted the researchers by telephone. Once the potential participant agreed to participate, a time was set to meet, and they were informed about the study and asked to sign an informed consent form before the interview. All participants agreed to participate and signed an informed consent form before the interview.

All participants were paid approximately US\$5 or Rp. 50,000 for their participation. Audio recordings of all interviews were made digitally and transcribed verbatim by the researcher team and a transcription service.

Data Collection

Data for this study were collected from individual face-to-face in-depth interviews conducted between July 2019 and November 2019. The interviews were scheduled at a date and time each participant chose and lasted 45 minutes to 1.5 hours. In cases where further clarification was needed, an additional interview was conducted over the phone. All interviews were conducted in a private room at the NGO by the researcher team.

The interview questions were developed by the research team, guided by a literature review and consultation with a professor in the faculty of nursing who has expertise in qualitative methods. All research team members had a nursing background, with three female researchers (SY, AYN, and RI) and one male researcher (CE). In addition, two researchers had PhD degrees (SY and RI), one had a doctoral degree (AYN), and one had a master's degree (CE).

The main interview question was, "Please tell me about your experience taking ART, and what strategies did you use to stay adherent to your medication?" Explanatory questions were asked during the interview, such as "What happened next?", "What did you do then?", and "How did you manage it?" based on the situation that the participants mentioned.

Subsequent interviews were used to clarify and elaborate in more detail about their information during the interview. All interview transcriptions were open-coded line-by-line, with the actual information from the participants' wording used as labeling codes. The researchers also made notes about participants' behavior, expression, tone, and other details during the interviews. All interviews were audio-recorded with participants' consent and transcribed using professional services. To ensure the accuracy of the data, the researchers compared the transcripts with the audio tape recording of all the interviews. Data collection was terminated when it was determined that theoretical saturation had occurred, meaning no new meaningful data were observed, and no new categorical properties or dimensions were identified.

Data Analysis

The grounded theory methodology proposed by Corbin and Strauss (2008) was used for data analysis. All data analysis was done manually by the research team. Data analysis was conducted simultaneously with data collection using open, axial, and selective coding methods. Initial coding was done through open coding, which involved identifying, labeling, and conceptualizing the phenomena experienced by the participants by reading all transcribed data, which was then categorized based on their similarity (Corbin & Strauss, 2008).

Axial coding was used to search for answers to questions such as where, how, when, and with what. The categories were derived through open coding, and their relationship was examined through continuous comparison of the emerged codes and their meaning and concept. Selective coding involves identifying the main categories and their relationship between the concept and the initial framework of the theory. The researchers formulated a theory regarding the process of adherence among PLWH and a highly abstract core category in which to integrate the relationships among all categories found during data analysis.

Trustworthiness/Rigor

The application of four criteria for trustworthiness proposed by Lincoln and Guba (1985), namely credibility, dependability, confirmability, and transferability, demonstrated rigor in this study. To establish credibility, investigator triangulation was conducted where each research team member read all manuscripts, presented them during research meetings for discussion and comparison with previous data collection, and finalized analysis and coding. The summary finding, including quote results, was provided to three participants, and their opinions were sought. All three participants agreed with the results. The data source, coding, and categorization mechanism were disclosed to maintain dependability. Confirmability was maintained by emphasizing how the categories emerged and including direct quotations from all participants. Finally, transferability was achieved by providing rich contextual information about the situation during data collection.

Ethical Considerations

The study was approved by the Committee on Human Research of the Faculty of Nursing, University Indonesia (Ethical Number: SK-173/UN2.F12.D1.2.1/ETIK.FIK.2019). Before the interviews, all participants had signed the informed consent form. Furthermore, the research team ensured that all information obtained in this study would be used for analysis and publication only. All participants' names were anonymous, and all data were kept confidential.

Results

In this study, a total of 21 respondents with a median age of 30 years participated. Among the participants, 57.2% were female, 57.7% had a senior high school education level. The duration of ART use among the participants ranged from 1 to 5 years. The majority of the participants were Muslim (90.4%) and employees (53.5%). Fourteen participants (66.6%) also have 1-2 children (Table 1).

The process of adhering or not adhering to ART is described as one's self-awareness of ART, which has three phases: initiating ART, missing the connection, and taking control. Throughout this process, the participants applied several strategies, including how they dealt with stigma, in order to adhere to their ART. This study focused on developing a theoretical model to understand the process of adherence or non-adherence to ART for PLWH, and the model explains several categories, conditions, environments, and consequences (Figure 1).

Table 1 Demographic characteristics of the participants (N = 21)

Characteristics	Number	percentage
Gender		
Male	9	42.8
Female	12	57.2
Age (years)		
21-25	2	3.5
26-30	3	14.4
31-40	14	66.6
>40	2	3.5
Religion		
Islam	19	90.4
Christian	2	9.6
Education		
Elementary school	1	4.7
Junior high school	3	14.1
Senior high school	12	57.7
Senior vocational	2	9.4
Diploma/Bachelor's degree	3	14.1
Occupation		
Employee	11	53.5
Self-employee	8	38
Housewife	2	8.5
Marital status		4.0
Single	3	4.2
Married	12	57.1
Widow/widower	6	28.5
Number of children	0	00.5
0 (None)	6	28.5
1-2	14	66.6
>2	1	4.9
Duration of ART (years) 1-3	0	20
1-3 4-5	8 6	38 28.5
4-5 >5	7	26.5 32.5
<i>></i> 0		32.5

Core Category: Self Awareness of ART

The theoretical construct: Self-awareness was identified as the central core theme that integrated the previous categories Initiate ART, Missing the connection, and Taking control. This core theme, self-awareness, explains the ART adherence process among PLWH. Although participants realize that several factors may influence them to adhere to their ART, they know that self-awareness of taking ART regularly is the key to maintaining adherence.

I understand that all people like me (living with HIV) already know that taking ART regularly is important for their health. But why are there still a lot of people who do not want to take their medication regularly? It is because the willingness to take ART does not come from them but from their doctor, nurse, or family. If you really want to take your ART regularly, you have to have high motivation from yourself, not from others. If you do, you can combat all obstacles you will face to maintain adherence to your ART [Participant 1]

Phase 1: Initiating ART

Phase 1 (Initiating ART) began when the participant recognized that non-adherence could lead to serious health problems. The problems of initiating ART included understanding the importance of ART and making the decision to begin ART treatment

Understanding the importance of ART. At the same time that the participants discovered they were HIV positive, they received information about their health and ART treatment from their health practitioner. As a result, the participants

generally understood that they needed to do something to improve and maintain their health.

I need to stay healthy. That's why I am here now, to see the doctor. The doctor prescribed me ART that I have to take for the rest of my life. [Participant 8]

Making the decision to start ART. The participants received information about ART once they knew they were HIV positive. For example, one participant explained how they began ART.

At the beginning of my HIV status, I was informed by the doctor to take ART. She said that these ARTs could help me stay healthy. Initially, my CD4 value was high, but she said I still needed to take ART. I was thinking, if I am taking ART, then it means that I will take ART for the rest of my life, but can I really take it regularly? [Participant 3]

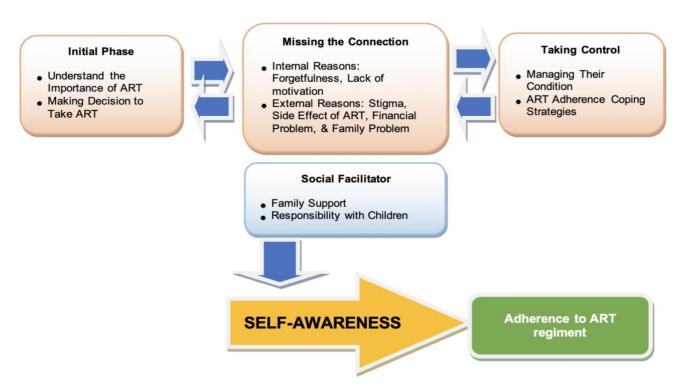


Figure 1 The theoretical model of adherence to ART

Phase 2: Missing the connection

Missing the connection is described as a situation where the participant cannot take their ART regularly. Mostly, participants who missed the connection show less consistent behavior with their ART. Although they acknowledge the importance of ART, they do not take their medication.

Forgetfulness was the commonly described reason by the participants for not taking their medication. Thus, this became their reason for non-adherence:

Actually, the reason that I do not take my medication regularly is, yeah, I forget to take it, miss. As you know, I am a housewife with two children and am busy taking care of my children. So, in the morning, at 9:00 am, I am supposed to take ART, but because I am busy with my children, I forget to take it. Then I realize it is already noon, and I have not taken my medication in the morning. So, that's what happened. [Participant 5]

Marital problems were another reason that prevented a participant from taking their medication.

I have a conflict with my husband. Once he knew that I had HIV, he easily got mad. He is always mad at me. Sometimes, he is angry without any reason. I was thinking that I wanted to complain by not taking my medication. He did not support me; he did not understand my situation. In this situation, why should I take my

medication? No, I complained by not taking my medication. [Participant 6]

The side effects of ART, such as nausea and vomiting, were identified by some participants as their reason for not taking their ART. One participant said:

This ART always made me vomit all the time, so I stopped it. I do not want to take it anymore. [Participant 8]

Another side effect was a change in skin color. One participant said:

This ART had a bad side effect on my skin. As you can see, my skin is getting dark. See the skin of my hand. In the past, I had very light skin. However, since I started taking ART last year, my skin has become dark and is not glowing anymore. I then stopped taking my ART and asked my physician to change my ART. [Participant 11]

Several external factors have been identified as the reason for non-adherence, such as the social stigma of HIV, financial problems, and no support from family. One participant mentioned one instance when she had to go out of town:

I brought my medication, yeah, ART, because I have to take it every morning and afternoon. However, sometimes when I hung

out with my friends, I was uncomfortable taking medicine. I thought it would be shameful if my friends knew that I was infected with HIV. So, they may not want to be my friend anymore. I don't want to take that risk. So, I didn't take the ART at the time. [Participant 2]

Social facilitator

The participant said they received social and emotional support from their family and community. For example, one participant said:

My husband also reminds me when it is time to take my medicine before we sleep at night. He said to me, 'Mom, do not forget to take your medication. [Participant 5]

One participant said that all her family members know her HIV status and give her support in regularly taking her ART:

My husband, sibling, my aunty, and all my big family, including my mom and father, know my HIV status. But they understood and accepted me and did not treat me differently. If we had family gatherings together, they would remind me to take my medication, If I forgot it. So, I can take it with no worry about my HIV status. [Participant 5]

All the participants who have children described that having the responsibility of taking care of their children helped them with the self-discipline necessary to achieve adherence to the ART regimen. Most of the participants, particularly mothers who have children, said that children are a gift from God and that they are responsible for taking care of them.

I have one child, a daughter, 10 years old. She is HIV-negative. I want to see her grow up, marry, and have a family. This is my responsibility as a mother. If it is not me, who else will take care of her? Therefore, I have to stay healthy and take my medicine regularly. I know that if I take my ART regularly, I will look like a normal person and not like a sick person. [Participant 9]

Phase 3: Taking control

The process of taking control describes the capabilities of participants to deal with their condition. Several categories in this phase include managing their condition and coping strategies.

Managing their condition. In this phase, the participants tried to manage their bodies and were highly motivated to adhere to ART. Several factors influenced their motivation, such as wanting to stay healthy, having a bad experience with non-adherence to ART, and worrying about developing resistance to ART from non-adherence.

I take my medication regularly. I realize that ART medication can make me look like a normal person as healthy person. So, I always motivate myself to take my medication to stay healthy. [Participant 3]

ART adherence coping strategies. Several strategies were identified, such as using alarms, family support, and reminders from peer groups. For example, one participant shared her story about trying to match her medication schedule with her husband's.

I managed my schedule of taking medicine to be at the same time as my husband's. In the beginning, my schedule was at 8:00 am. But eventually, I changed it to 6:00 am so that I could take medicine with my husband. [Participant 9] Another strategy to conceal their HIV status with ART was changing their ART bottle into a vitamin one. As one participant mentioned:

I know that people in my workplace may recognize me as having HIV once they see my ART. However, I still need to take my medicine regularly. So, I tricked them by changing my ART bottle into a vitamin bottle. If people ask me what kind of drug I take, I will say I take vitamins. People will not know my HIV status because everybody takes vitamin daily. [Participant 10]

Setting the alarm as a reminder was also mentioned by participants.

I know that sometimes I forget to take my medication. So, I set my alarm using my cellphone twice a day. I usually set it early in the morning to 6:00 am and set it to 7:00 pm at night. This is just to remind me. As a housewife, I forget to take my medication because I am busy as a mother, such as when doing laundry and cooking. [Participant 6]

Discussion

To the best of our knowledge, this is the first study that develops a theoretical model for the process of adherence among people living with HIV (PLWH) in Indonesia. The core category, "self-awareness," refers to how participants adhere to their antiretroviral therapy (ART). Our findings suggest that self-awareness is a process rather than an instant occurrence.

The first step in enhancing our understanding of ART adherence is to pay attention to the initial phase, where patients receive information and start ART. In this phase, it is important to inquire about their perceptions and understanding of the importance of taking ART regularly, even before deciding to start ART. Several studies have demonstrated an association between poor adherence and a lack of knowledge (Martiana et al., 2019; Weaver et al., 2014).

In our study, participants identified several conditions that can hinder an individual's ability to adhere to treatment, such as forgetting to take medication, fear of stigma, lack of motivation, and ART side effects. We found that forgetting to take medication was the most common reason for nonadherence to ART. This unintentional reason is similar to what was found in previous studies as the main cause of poor adherence (Hadaye et al., 2020; Sefah et al., 2022). PLWH stigma is also cited as a factor that contributes to nonadherence. Several studies have highlighted that stigma is the major cause of a patient's non-adherence (Camacho et al., 2020; Martiana et al., 2019; Rudolph et al., 2022; Shrestha et al., 2019; Stecher et al., 2023; Zeng et al., 2020). Stigma exists in Indonesia, particularly for women living with HIV, and it is the primary cause of non-adherence to ART (Ismail et al., 2022; Nurfalah et al., 2019; Yona et al., 2021). Internal factors, such as lack of motivation and forgetfulness, were also mentioned as barriers to ART adherence (Mugo et al., 2023; Sefah et al., 2022; Shrestha et al., 2019). A mixed-method study by Sefah et al. (2022) found that lower adherence to ART was associated with patients' belief in herbal medicine and, from qualitative analysis, low motivation arising from pill fatigue, forgetfulness, frequent stock out of drugs, long waiting times, and worrying side-effects became barriers to ART adherence. Measures that can improve patient satisfaction with ART services and better assessment of adherence are

included in strategies that ensure improved adherence and health facility-related activities.

A side effect of ART that was also mentioned as a reason for non-adherence is physical changes, such as lipodystrophy and changes in skin color, which lead to depression due to poor body image. This outcome is similar to those of previous studies (Byrd et al., 2019; Hadaye et al., 2020; Zeng et al., 2020). Some participants also mentioned a lack of motivation to continue their medication due to boredom. This reason made it difficult for them to integrate their activities with their ART. However, although participants mentioned a lack of motivation, they also said that having a high self-awareness of ART is essential to deal with this problem.

Taking control is the second step in broadening our understanding of the adherence process. Taking control refers to how individuals manage their condition and develop strategies to adhere to ART. In this study, participants employed multiple strategies to adhere to their medication, recognizing that adherence is essential for PLWH but needs to be tailored to each patient's lifestyle. Patients who can incorporate treatment into their daily routines are more likely to be adherent. Several strategies were mentioned by participants, including using alarms, family support, and peer group pressure. Implementation of innovative methods is essential to ensure ART adherence.

Some studies have highlighted the importance of PLWH involvement in the ART medication process, such as ART distribution, planning, and monitoring activities (Gabster et al., 2022; Goparaju et al., 2017). For example, a qualitative study by Gabster et al. (2022) in Panama found that structural barriers, such as difficult access to ART care due to travel costs, ART shortages, and uncooperative Western/Traditional medical systems, became barriers to ART adherence among PLWH in Panama. Likewise, PLWH receives their ART medications from a pharmacy or hospital in Indonesia, so it is difficult for them to become involved in the ART therapy process (Indonesian Ministry of Health, 2021).

Social support from a spouse, such as taking care of children, facilitated medication adherence and retention of HIV care. This finding is consistent with research reported in other countries (King et al., 2021; Maragh-Bass et al., 2021; Mi et al., 2020; Oliveira et al., 2020). In addition, receiving love and support from family members, including spouses, can facilitate participants' adherence to their medication (Mi et al., 2020). In previous studies, adequate support and a positive mindset have been shown to enhance ART adherence (King et al., 2021; Maragh-Bass et al., 2021; Oliveira et al., 2020). This finding is essential in Indonesian society, where the concept of family responsibility is highly valued. With this concept, the family will stay together through difficult times, including providing a support system for a sick family member (Sianturi & Dorothea, 2020).

Finally, the research team identified the core category and theoretical construct, self-awareness, as the central theme that integrated the previous categories of initiating ART, missing the connection, and taking control. This construct explains the process of adherence among PLWH in Indonesia. The participants in this study realized that several factors could influence their adherence to ART, but their self-awareness of taking their medication regularly is the key to maintaining adherence. These findings highlight the importance of

individual self-awareness and the mindfulness strategies that have been proven to enhance adherence to ART.

As Kerrigan et al. (2018), self-awareness of ART is one of the mindfulness strategies proven to enhance adherence to ART (Sibinga et al., 2022). This method involves becoming aware of the conditions that cause or remove distortions or biases, leading to positive, healthy behaviors, including adherence to the medication regimen. Mindfulness is similar to the Buddhist concept of "Sati", which means "memory," and is closely related to "Sarati", meaning "process." It emphasizes a close and constant connection between being fully present, observing, sitting with, and accepting (Brown & Ryan, 2003). Thus, mindfulness focuses on memory and attention functions (Thera, 1962). The present study underscores the significance of individual self-awareness in achieving better adherence rates. Individuals who perceive their ART as necessary can develop several strategies to take their medication regularly. Several studies have also identified mindfulness training as one of the strategies that can help patients improve adherence to their medical treatment and decrease HIV viral load (Salmoirago-Blotcher & Carey, 2018; Sibinga et al., 2022).

The study found that highly self-aware participants employed multiple strategies to continue adhering to their medication, such as adjusting their medication with ART. This finding is similar to a previous study that found geriatric patients adjusted their medication according to their daily activities (Dworakowska et al., 2019). The study also found that some participants dealt with stigma by changing the bottle of their ART to a bottle of vitamins, allowing them to take their medication without worrying about stigma.

Implications for Nursing Practice and Healthcare Policy

Our findings suggest that factors such as lack of motivation, ART side effects, and stigma can easily trigger nonadherence to ART. High self-awareness of the importance of taking ART is critical for staying adherent to the ART regimen. Moreover, frequent and ongoing social support is needed rather than focusing only on pill counts and viral load. Nurses can assist in identifying potential support persons and the kind of necessary information regarding ART therapy. For some PLWH, this information may include managing stigma while taking ART in public places. By encouraging PLWH to develop coping strategies for taking ART, they will remain adherent, regardless of the situation.

Limitations

Since this study used a retrospective perspective from participants, recall bias may occur. Additionally, this study was conducted before the COVID-19 pandemic and only represented the situation of participants before the pandemic. Furthermore, due to the methodology design, the study's results may not generalize to the larger population since it was conducted only in Jakarta.

Conclusion

Self-awareness of the importance of adhering to ART was identified as the core factor that can describe the process of adherence or non-adherence to ART. Understanding the concept of ART and the importance of self-control in taking ART regularly is the most crucial factor for ART adherence.

Declaration of Conflicting Interest

The authors declared no potential conflicts of interest concerning the research, authorship, or publication of this article.

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Authors' Contributions

SY contributed to conceptualization, methodology, and data analysis. CE contributed to data collection and draft manuscript. AYN contributed to conceptualization and data collection. RI contributed to data analysis, discussion, and references. All authors were accountable in each step of the study and approved the final version of the article.

Authors' Biographies

Sri Yona, S.Kp., M.N., Ph.D. is an Assistant Professor at the Department of Medical Surgical Nursing, Faculty of Nursing, Universitas Indonesia, Depok, West Java, Indonesia.

Ns. Chiyar Edison, S.Kep., M.Sc. is a Lecturer at the Department of Medical Surgical Nursing, Faculty of Nursing, Universitas Indonesia, Depok, West Java, Indonesia.

Dr. Astuti Yuni Nursasi, S.Kp., M.N. is an Assistant Professor at the Department of Community Nursing, Faculty of Nursing, Universitas Indonesia, Depok, West Java, Indonesia.

Rita Ismail, PhD, RN, MPH, MTD (HE) is an Assistant Professor at the Ministry of Health Republic of Indonesia, Poltekkes Kemenkes Jakarta III, Bekasi, Indonesia, 12120, West Java, Indonesia.

Data Availability

The datasets generated during and analyzed during the current study are not publicly available due to privacy issues of the participants (vulnerable population).

Declaration of use of AI in Scientific Writing

Nothing to declare.

References

- Agnes, Y. L. N., & Songwathana, P. (2021). Understanding stigma and coping strategies among HIV-negative Muslim wives in serodiscordant relationships in a Javanese community, Indonesia. *Belitung Nursing Journal*, 7(5), 409-417. https://doi.org/10.33546/bnj.1600
- Audi, C., Jahanpour, O., Antelman, G., Guay, L., Rutaihwa, M., van de Ven, R., Woelk, G., & Baird, S. J. (2021). Facilitators and barriers to antiretroviral therapy adherence among HIV-positive adolescents living in Tanzania. *BMC Public Health*, 21(1), 1-8. https://doi.org/ 10.1186/s12889-021-12323-1
- Boyd, M. A., Moore, C. L., Molina, J.-M., Wood, R., Madero, J. S., Wolff, M., Ruxrungtham, K., Losso, M., Renjifo, B., & Teppler, H. (2015). Baseline HIV-1 resistance, virological outcomes, and emergent resistance in the SECOND-LINE trial: An exploratory analysis. *The Lancet HIV*, 2(2), e42-e51. https://doi.org/10.1016/S2352-3018(14) 00061-7
- Brown, K. W., & Ryan, R. M. (2003). The benefits of being present: Mindfulness and its role in psychological well-being. *Journal of Personality and Social Psychology*, *84*(4), 822-848. https://psycnet.apa.org/doi/10.1037/0022-3514.84.4.822
- Byrd, K. K., Hou, J. G., Hazen, R., Kirkham, H., Suzuki, S., Clay, P. G., Bush, T., Camp, N. M., Weidle, P. J., & Delpino, A. (2019). Antiretroviral adherence level necessary for HIV viral suppression using real-world data. *Journal of Acquired Immune Deficiency Syndromes* (1999), 82(3), 245-251. https://doi.org/10.1097%2FQAI. 00000000000002142
- Camacho, G., Kalichman, S., & Katner, H. (2020). Anticipated HIV-related stigma and HIV treatment adherence: The indirect effect of medication concerns. AIDS and Behavior, 24, 185-191. https://doi.org/10.1007/ s10461-019-02644-z

- Castillo-Mancilla, J. R., Cavassini, M., Schneider, M. P., Furrer, H., Calmy, A., Battegay, M., Scanferla, G., Bernasconi, E., Günthard, H. F., & Glass, T. R. (2021). Association of incomplete adherence to antiretroviral therapy with cardiovascular events and mortality in virologically suppressed persons with HIV: the Swiss HIV Cohort Study. *Open Forum Infectious Diseases*, 8(2), ofab032. https://doi.org/10.1093/ofid/ofab032
- Centers for Disease Control and Prevention. (2021). ART adherence. https://www.cdc.gov/hiv/clinicians/treatment/art-adherence.html
- Corbin, J., & Strauss, A. (2008). Basics of qualitative research: Techniques and procedures for developing grounded theory (3rd ed.). SAGE Publications. https://doi.org/10.4135/9781452230153
- Dworakowska, A. M., Aniszewska, A., & Kozłowska-Wojciechowska, M. (2019). Older adults' strategies to prevent episodic medication non-adherence: Results from a qualitative study. European Geriatric Medicine, 10, 327-330. https://doi.org/10.1007/s41999-018-00156-y
- Edison, C., Setyowati, S., & Waluyo, A. (2021). Pengalaman aktivitas spiritual pada orang dengan HIV/AIDS (ODHA) dalam menjalani proses penyakitnya [Experience of spiritual activity in people with HIV/AIDS (PLWHA) in going through their disease process]. Faletehan Health Journal, 8(3), 216-222. https://doi.org/10.33746/fhj.v8i03.209
- Fahriati, A. R., Indah, F. P. S., Satria, B. M., & Mutoharoh, A. A. (2021). Faktor-faktor yang berhubungan dengan kepatuhan minum antiretroviral pada ODHA (orang dengan HIV/AIDS) berdasarkan systematic literature review [Factors related to antiretroviral adherence in PLHIV (people living with HIV/AIDS) based on a systematic literature review]. PHRASE (Pharmaceutical Science) Journal, 1(1), 29-46. http://dx.doi.org/10.52031/phrase.v1i1.157
- Farr, A. M., Johnston, S. S., Ritchings, C., Brouillette, M., & Rosenblatt, L. (2016). Persistence, adherence, and all-cause healthcare costs in atazanavir-and darunavir-treated patients with human immunodeficiency virus in a real-world setting. *Journal of Medical Economics*, 19(4), 386-396. https://doi.org/10.3111/13696998.2015. 1128942
- Gabster, A., Socha, E., Pascale, J. M., Cabezas Talavero, G., Castrellón, A., Quiel, Y., Gantes, C., & Mayaud, P. (2022). Barriers and facilitators to antiretroviral adherence and retention in HIV care among people living with HIV in the Comarca Ngäbe-Buglé, Panama. *PloS One*, 17(6), e0270044. https://doi.org/10.1371/journal.pone.0270044
- Glaser, B. G. (1998). Doing grounded theory: Issues and discussions. Mill Valley, CA: Sociology Press. https://books.google.co.th/books?id=XSt mQgAACAAJ
- Glaser, B. G. (2002). Conceptualization: On theory and theorizing using grounded theory. *International Journal of Qualitative Methods*, 1(2), 23-38. https://doi.org/10.1177/160940690200100203
- Glass, T. R., Sterne, J. A. C., Schneider, M.-P., De Geest, S., Nicca, D., Furrer, H., Günthard, H. F., Bernasconi, E., Calmy, A., & Rickenbach, M. (2015). Self-reported nonadherence to antiretroviral therapy as a predictor of viral failure and mortality. AIDS 29(16), 2195-2200. https://doi.org/10.1097/QAD.0000000000000782
- Goparaju, L., Praschan, N. C., Warren-Jeanpiere, L., Experton, L. S., Young, M. A., & Kassaye, S. (2017). Stigma, partners, providers and costs: Potential barriers to PrEP uptake among US women. *Journal of AIDS & Clinical Research*, 8(9), 730. https://doi.org/10.4172%2F215 5-6113.1000730
- Hadaye, R. S., Jambhale, V. B., & Shastri, S. (2020). Assessment of adherence and factors contributing to non-adherence among patients on anti-retroviral therapy in a tertiary care hospital: A cross sectional study. *Journal of Family Medicine and Primary Care*, 9(4), 1921-1926. https://doi.org/10.4103%2Fjfmpc_jfmpc_1138_19
- Harison, N., Waluyo, A., & Jumaiyah, W. (2020). Pemahaman pengobatan antiretroviral dan kendala kepatuhan terhadap terapi antiretroviral pasien HIV/AIDS [Understanding of antiretroviral treatment and constraints to adherence to antiretroviral therapy in HIV/AIDS patients]. JHeS (Journal of Health Studies), 4(1), 87-95. https://doi.org/10.31101/jhes.1008
- Haryadi, Y., Sumarni, S., & Angkasa, M. P. (2020). Jenis pekerjaan dan tingkat pendidikan mempengaruhi kepatuhan minum obat antiretroviral (ARV) pada pasien HIV/AIDS [Type of work and level of education affect adherence to antiretroviral medication (ARV) in HIV/AIDS patients]. Jurnal Lintas Keperawatan, 1(1). https://doi.org/ 10.31983/jlk.v1i1.6446
- Indonesian Ministry of Health. (2019). Report on the Development of HIV AIDS and Sexually Transmitted Diseases (PIMS) for the second

- quarter of 2019 [in Bahasa]. https://siha.kemkes.go.id/portal /files upload/Laporan HIV TW II 2019Final a.pdf
- Indonesian Ministry of Health. (2021). Report on the Development of HIV AIDS and Sexually Transmitted Diseases (PIMS) for the second quarter of 2022 [in Bahasa]. https://siha.kemkes.go.id/portal/files_upload/Laporan_TW_1_2022.pdf
- Ismail, R., Voss, J. G., Yona, S., Nurachmah, E., Boutain, D., Lowe, C., John-Stewart, G., & Woods, N. F. (2022). Classifying stigma experience of women living with HIV in Indonesia through the social ecological model. *Health Care for Women International*, 43(1-3), 345-366. https://doi.org/10.1080/07399332.2021.1929989
- Kerrigan, D., Grieb, S. M., Ellen, J., & Sibinga, E. (2018). Exploring the dynamics of ART adherence in the context of a mindfulness instruction intervention among youth living with HIV in Baltimore, Maryland. AIDS Care, 30(11), 1400-1405. https://doi.org/10.1080/09540121.2018. 1492699
- King, E. J., Yakovleva, A., Lisecki, S. R., Shastina, E., Sukhova, N., Titina, E., Legchilova, D., Evdokimova, I., & Godunova, J. (2021). Social support and postpartum adherence to HIV treatment: A community-based participatory research study in Russia. *European Journal of Public Health*, 31(1), 63-67. https://doi.org/10.1093/eurpub/ckaa133
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. California: Sage Publications.
- Mahathir, M., Wiarsih, W., & Permatasari, H. (2021). "Accessibility": A new narrative of healthcare services for people living with HIV in the capital city of Indonesia. *Belitung Nursing Journal*, 7(3), 227-234. https://doi.org/10.33546/bnj.1409
- Maragh-Bass, A. C., Gamble, T., El-Sadr, W. M., Hanscom, B., & Tolley, E. E. (2021). Examining stigma, social support, and gender differences in unsuppressed HIV viral load among participants in HPTN 065. *Journal of Behavioral Medicine*, 44, 159-171. https://doi.org/10.10 07/s10865-020-00186-7
- Martiana, I., Waluyo, A., & Yona, S. (2019). Assessing the relationship between knowledge of antiretroviral therapy and stigma regarding adherence to ART among men who have sex with men. *Enfermería Clínica*, 29, 321-325. https://doi.org/10.1016/j.enfcli.2019.06.004
- Mi, T., Li, X., Zhou, G., Qiao, S., Shen, Z., & Zhou, Y. (2020). HIV disclosure to family members and medication adherence: role of social support and self-efficacy. AIDS and Behavior, 24, 45-54. https://doi.org/10.1007/s10461-019-02456-1
- Mugo, C., Kohler, P., Kumar, M., Badia, J., Kibugi, J., Wamalwa, D. C., Agot, K., & John-Stewart, G. C. (2023). Individual-, interpersonal-and institutional-level factors associated with HIV stigma among youth in Kenya. AIDS and Behavior, 1-13. https://doi.org/10.1007/s10461-023-03982-9
- Noble, H., & Mitchell, G. (2016). What is grounded theory? *Evidence-Based Nursing*, 19(2), 34-35. http://dx.doi.org/10.1136/eb-2016-102306
- Nuraidah, N., Wanda, D., Hayati, H., Rachmawati, I. N., & Waluyo, A. (2022). "I can live a normal life": Exploring adherence to antiretroviral therapy in Indonesian adolescents living with HIV. *Belitung Nursing Journal*, 8(2), 108-114. https://doi.org/10.33546/bnj.2024
- Nurfalah, F., Yona, S., & Waluyo, A. (2019). The relationship between HIV stigma and adherence to antiretroviral (ARV) drug therapy among women with HIV in Lampung, Indonesia. *Enfermería Clínica*, 29, 234-237. https://doi.org/10.1016/j.enfcli.2019.04.138
- Oliveira, R. d. S., Primeira, M. R., Santos, W. M. d., Paula, C. C. d., & Padoin, S. M. d. M. (2020). Association between social support and adherence to anti-retroviral treatment in people living with HIV. Revista Gaúcha de Enfermagem, 41. https://doi.org/10.1590/1983-1447. 2020.20190290
- Rocheleau, G., Brumme, C. J., Shoveller, J., Lima, V. D., & Harrigan, P. R. (2018). Longitudinal trends of HIV drug resistance in a large Canadian cohort, 1996–2016. *Clinical Microbiology and Infection*, 24(2), 185-191. https://doi.org/10.1016/j.cmi.2017.06.014
- Rudolph, A. E., Dembo, R. S., Tobin, K., & Latkin, C. (2022). Perceived HIV treatment norms modify the association between HIV-related stigma and adherence to antiretroviral therapy among persons living with HIV in Baltimore, Maryland. *AIDS and Behavior*, 1-12.
- Salmoirago-Blotcher, E., & Carey, M. P. (2018). Can mindfulness training improve medication adherence? Integrative review of the current

- evidence and proposed conceptual model. *Explore*, *14*(1), 59-65. https://doi.org/10.1016/j.explore.2017.09.010
- Sefah, I. A., Mensah, F., Kurdi, A., & Godman, B. (2022). Barriers and facilitators of adherence to antiretroviral treatment at a public health facility in Ghana: A mixed method study. *Hospital Practice*, 50(2), 110-117. https://doi.org/10.1080/21548331.2022.2045132
- Shrestha, R., Altice, F. L., & Copenhaver, M. M. (2019). HIV-related stigma, motivation to adhere to antiretroviral therapy, and medication adherence among HIV-positive methadone-maintained patients. *Journal of Acquired Immune Deficiency Syndromes* (1999), 80(2), 166-173. https://doi.org/10.1097%2FQAI.000000000001891
- Sianturi, S. R., & Dorothea, C. B. (2020). Hubungan dukungan keluarga dengan kepatuhan orang dengan HIV/AIDS minum obat ARV [Relationship between family support and adherence of people living with HIV/AIDS to taking ARV drugs]. *Journal of Applied Nursing (Jurnal Keperawatan Terapan)*, 6(2), 111-120. https://doi.org/10.31290/jkt.v6i2.1572
- Sibinga, E. M. S., Webb, L., Perin, J., Tepper, V., Kerrigan, D., Grieb, S., Denison, J., & Ellen, J. (2022). Mindfulness instruction for medication adherence among adolescents and young adults living with HIV: A randomized controlled trial. AIDS Care, 34(12), 1619-1627. https://doi.org/10.1080/09540121.2022.2105796
- Stecher, C., Palimaru, A. I., Odiit, M., Lunkuse, L., Walukaga, S., & Linnemayr, S. (2023). Barriers and facilitators of antiretroviral therapy (ART) adherence habit formation in Sub-Saharan Africa: Evidence from a qualitative study in Kampala, Uganda. Social Science & Medicine, 317, 115567. https://doi.org/10.1016/j.socscimed.2022. 115567
- Surur, A. S., Teni, F. S., Wale, W., Ayalew, Y., & Tesfaye, B. (2017). Health related quality of life of HIV/AIDS patients on highly active antiretroviral therapy at a university referral hospital in Ethiopia. BMC Health Services Research, 17(1), 1-8. https://doi.org/10.1186/s12913-017-2714-1
- Thera, N. (1962). The heart of buddhist meditation: Satipaṭṭhāna: A handbook of mental training based on the Buddha's way of mindfulness, with an anthology of relevant texts translated from the Pali and Sanskrit. London: Buddhist Publication Society.
- Weaver, E. R. N., Pane, M., Wandra, T., Windiyaningsih, C., & Samaan, G. (2014). Factors that influence adherence to antiretroviral treatment in an urban population, Jakarta, Indonesia. *PloS One*, 9(9), e107543. https://doi.org/10.1371/journal.pone.0107543
- World Health Organization. (2021). Summary of the global HIV epidemic 2021. https://www.who.int/data/gho/data/themes/hiv-aids
- Xu, J.-F., Ming, Z.-Q., Zhang, Y.-Q., Wang, P.-C., Jing, J., & Cheng, F. (2017). Family support, discrimination, and quality of life among ART-treated HIV-infected patients: A two-year study in China. *Infectious Diseases of Poverty*, 6(1), 1-10. https://doi.org/10.1186/s40249-017-0364-5
- Yona, S., Ismail, R., Nurachmah, E., Levy, J., & Norr, K. (2021). Gaining a "normal life": HIV-positive Indonesian female injection drug users in drug recovery. *Journal of Ethnicity in Substance Abuse*, 20(1), 117-134. https://doi.org/10.1080/15332640.2019.1598904
- Zeng, C., Li, X., Qiao, S., Yang, X., Shen, Z., & Zhou, Y. (2020). Anticipated stigma and medication adherence among people living with HIV: The mechanistic roles of medication support and ART selfefficacy. AIDS Care, 32(8), 1014-1022. https://doi.org/10.1080/ 09540121.2020.1728213
- Zhou, G., Li, X., Qiao, S., Shen, Z., & Zhou, Y. (2018). Influence of side effects on ART adherence among PLWH in China: the moderator role of ART-related knowledge. AIDS and Behavior, 22, 961-970. https://doi.org/10.1007/s10461-017-1791-9
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