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Research Article

Correlation between knowledge level, side effect severity, family support, and antiretroviral therapy adherence in HIV/AIDS patients in Greater Malang, East Java, Indonesia

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Abstract

Human Immunodeficiency Virus (HIV) is a virus that attacks and weakens the human immune system, leading to Acquired Immune Deficiency Syndrome (AIDS) symptoms. East Java is one of the provinces in Indonesia with a high HIV prevalence. Antiretroviral therapy (ART) is a critical approach to slow down the growth rate of HIV since no medicine has been found for HIV/AIDS patients. Therefore, high adherence to ART is necessary to reduce viral replication and prevent the development of resistance. This study aimed to investigate the correlation between knowledge level, side effect severity, family support, and ART adherence in HIV/AIDS patients. This observational analytic study with a cross-sectional design was conducted in September-October 2022 at the Netral Plus Indonesia Foundation and Malang Islamic Hospital. The study included 55 HIV/AIDS patients, and the Spearman correlation test was used to analyze the data. There was no significant relationship between knowledge level, side effects, and adherence to ART treatment ($p = 0.959$; $p = 0.719$). However, family support was found to be significantly related to adherence to ART treatment ($p = 0.004$). The findings of this study suggest that family support is a crucial factor in the adherence to ART treatment among HIV/AIDS patients.

Keywords

Antiretroviral therapy, drug side effects, family support, HIV/AIDS, knowledge level, people living with HIV/AIDS, therapeutic adherence

Introduction

Human Immunodeficiency Virus (HIV) is a virus that attacks and weakens the human immune system, reducing the body's ability to fight off various diseases. HIV causes a set of symptoms known as Acquired Immune Deficiency Syndrome (AIDS) (Mardalena 2020). HIV/AIDS has become an epidemic in Indonesia, as it is currently ranked fifth among Asian countries with the highest risk of HIV/AIDS (Jusriana et al 2020). Since September 2013, East

Java province and five other provinces, namely DKI Jakarta, Papua, Bali, Riau, and West Java, have been designated as an area with concentrated HIV prevalence. In 2020, in East Java, there were 7,395 reported cases of HIV and 467 cases of AIDS, resulting in 36 deaths (7.7%). The number of HIV/AIDS cases in East Java has been increasing rapidly over time (East Java Provincial Health Office 2021).

Antiretroviral therapy (ART) is one of the methods used to slow down the rate of growth of HIV, as there is currently no cure for HIV/AIDS patients. ART is a combination of medications that work to slow down or suppress the growth of HIV in the body. Although it does not completely eliminate the virus, ART has successfully reduced the amount of HIV in the bloodstream of patients (Jusriana et al 2020). Since the introduction of ART, HIV/AIDS has transformed from a lethal to a chronic disease. ART given in combination is preferred over monotherapy to reduce the risk of virological failure and the development of resistance to ART (Panel on Antiretroviral Guidelines for Adults and Adolescents 2022).

The primary aim of managing HIV disease using combination antiretroviral therapy (ART) is to suppress viral replication and improve immune function, leading to enhanced patient outcomes and quality of life (Tseng et al. 2012; Yunita et al. 2020). Besides, the secondary objectives include promoting long-term adherence, avoiding drug interactions, minimizing toxic side effects, simplifying treatment regimens, reducing drug costs, managing comorbid conditions, and achieving an undetectable viral load to prevent HIV transmission (Tseng et al. 2012). Achieving an undetectable viral load requires a minimum compliance level of 82–95% for people living with HIV/AIDS (PLWHA) (Chatha et al. 2020). However, adherence to ART by PLWHA in low- and lower-middle-income countries is 1.6 times lower than in upper-middle- or high-income countries (Bijker et al. 2017). Low adherence is very detrimental because it can accelerate the development of ART-resistant viruses and reduce the effectiveness of ART in preventing HIV transmission (Hansana et al. 2013). Therefore, identifying the factors that contribute to low adherence to ART is critical.

In Indonesia, there is currently no available data on the prevalence of resistance to ART, although several studies in various regions have investigated ART resistance (Nadia et al. 2022). A study by Merati et al. (2021) found that 16.7% of patients experienced resistance to ART classes of Nucleoside Reverse Transcriptase Inhibitor (NRTI) and Non-Nucleoside Reverse Transcriptase Inhibitor (NNRTI) (Merati et al. 2021). Therefore, the involvement of pharmacists is crucial in assisting patients and other healthcare providers in achieving the goals of ART treatment, mainly to prevent resistance, monitor adherence, and provide information about treatment to achieve therapeutic success (Tseng et al. 2012).

The objective of this study is to determine whether there is a correlation between knowledge level, side effect severity, family support, and adherence of HIV/AIDS patients in Greater Malang, East Java, Indonesia.

Methods

This research is observational analytic with a cross-sectional design conducted at the Netral Plus Indonesia Foundation and Malang Islamic Hospital, Malang City, Indonesia, from September to October 2022. The living area of the patients recruited for the study was Greater Malang, covering Malang City, Malang Regency, and Batu City. The inclusion criteria in the study were patients diagnosed with HIV and/or AIDS, at least 19 years old, currently receiving ART treatment, and willing to become research subjects by filling out an informed consent form. Meanwhile, the exclusion criteria were patients who were pregnant and/or received ART for less than one month.

The formula for sample size used in this research corresponds to the ordinal-ordinal correlational analysis formula (Dahlan 2019), as follows:

$$n = \left[\frac{Z\alpha + Z\beta}{0.5\ln\left(\frac{1+r}{1-r}\right)}\right]^2 + 3$$

$$n = \left[\frac{1.64 + 1.28}{0.5\ln\left(\frac{1+0.4}{1-0.4}\right)}\right]^2 + 3$$

$$n = 50.5 \approx 51$$

Note:

n = Number of research subjects.

$Z\alpha$ = Alpha standard deviation with a type 1 error set at 5%, which is 1.64 (Tyastirin and Hidayati 2017).

$Z\beta$ = Beta standard deviation with a type 2 error set at 10%, which is 1.28 (Tyastirin and Hidayati 2017).

r = Minimum correlation coefficient considered significant, set at 0.4 (Dahlan 2019).

Based on the formula for calculating the sample size, the required sample size in this study was 51 patients. Sampling was carried out using a non-random sampling method with a purposive sampling technique. A total of 55 patients who met the inclusion and exclusion criteria were successfully recruited into this study. Data collection was carried out using the direct interview method with PLWHA patients who came to the Voluntary Counseling and Testing (VCT) Polyclinic at Malang Islamic Hospital and using the Google forms for the Netral Plus Indonesia Foundation.

Data collection

This study utilized a questionnaire as a research instrument, which was divided into five parts: patient's identity along with the type of ART (antiretroviral therapy) and its frequency of use (see Appendix 1), assessment of knowledge level (see Appendix 2), assessment of side effect severity (see Appendix 3), assessment of family support (see Appendix 4), and assessment of adherence (see Appendix 5). The questionnaire for measuring knowledge level was adapted from the HIV Knowledge Questionnaire-18 (KQ-HIV-18) (Arifin et al. 2022). The questionnaire had already been translated

into Indonesian and validated by Arifin et al. (2022). The questionnaire for assessing side effect severity was adapted from Justice et al. (2001). To measure the level of adherence, the MARS-10 questionnaire (Medication Adherence Rating Scale) developed by Thompson et al. (2000) was used (Thompson et al. 2000). Both the MARS-10 questionnaire and the questionnaire for assessing side effect severity were translated into Indonesian by Brawijaya Language Center (BLC) in Malang, Indonesia, which is an excellent language development unit that follows international standards. The translation results were then adjusted to make the language more understandable for the general public. The family support questionnaire was adapted from an Indonesian-language questionnaire developed by Roslandari et al. (2020).

This study employed multiple questionnaires to evaluate various factors associated with HIV treatment. The questionnaire assessing knowledge about HIV disease and its transmission consisted of 18 statements, the questionnaire evaluating the severity of side effects consisted of 20 questions, the adherence questionnaire consisted of 10 questions, while the family support questionnaire contained 20 statements and was categorized into four groups based on instrumental, appraisal, informational, and emotional support. The knowledge questionnaire scores were classified as low (total score 0–5), moderate (total score 6–12), and good (total score 13–18) (Aryanto et al. 2018). The severity of side effects questionnaire was divided into four categories: no side effects (total score 0), mild (total score 1–26.3), moderate (total score 26.4–52.7), and severe (total score 52.8–80) (Srikartika et al 2019). The family support scores were categorized as low (total score 25–50%), moderate (total score 51–75%), and good (total score 76–100%) (Roslandari et al. 2020). Compliance levels were classified as non-adherent (total score 0–3), moderately adherent (total score 4–6), and adherent (total score 7–10) (Roslandari et al. 2020).

Data analysis

The validity of the side effect severity and adherence questionnaires was tested using the Pearson correlation test, with each question item considered valid if the value of r count > r table (0.361 for 30 respondents). The reliability of the questionnaires was assessed using the Cronbach's Alpha test, with a value >0.60 indicating reliability. To analyze the correlation between knowledge level, side effect severity, family support, and ART adherence, the Spearman correlation test was used. A p-value <0.05 indicated a statistically significant correlation.

Ethical clearance

The study has obtained ethical clearance from the Health Research Ethics Committee at Malang Islamic Hospital, Indonesia, through the ethical clearance decree number 11/KEPK.RSIUNISMA/VIII/2022.

Results

Table 1 shows patient demographic data, including the distribution of patients' residence, age, and gender, as well as the ART regimens they received. Most patients involved in this study were from Malang city (31 patients; 56.36%). Most of the patients belonged to the adult age category, ranging from 19 to 44 years (44 patients; 80%), with the majority of male (42 patients; 76.36%). The most common ART regimen was Tenovofir disoproxil fumarate 300 mg + Lamivudine 300 mg + Efavirenz 600 mg (TLE) (30 patients; 54.55%).

Table 1. Patient demographic data.

Characteristic	Frequency	Percentage (%)
Greater Malang Region		
Malang City	31	56.36
Malang Regency	22	40.00
Batu City	2	3.64
Total	**55**	**100.00**
Age		
19 – 44 years (adult)	44	80
45 – 59 years (middle-age)	11	20
Total	**55**	**100**
Gender		
Male	42	76.36
Female	13	23.64
Total	**55**	**100.00**
Type, Dose, dan Frequency of ART		
Tenovofir disoproxil fumarate 300 mg + Lamivudine 300 mg + Efavirenz 600 mg (TLE) once a day	30	54.55
Dolutegravir sodium 50 mg + Lamivudine 300 mg + Tenovofir disoproxil fumarate 300 mg (TLD) once a day	7	12.73
Lamivudine 150 mg + Zidovudine 300 mg twice a day, Nevirapine 200 mg twice a day	13	23.64
Tenovofir disoproxil fumarate 300 mg once a day, Lamivudine 150 mg once a day, Nevirapine 200 mg once a day	3	5.44
Lamivudine 150 mg + Zidovudine 300 mg twice a day, Efavirenz 600 mg once a day	2	3.64
Total	**55**	**100.00**

The distribution of factors that can correlate with adherence to ART is shown in Table 2, which includes variables such as knowledge of HIV and how it is transmitted, the degree of side effect severity, and family support. Among the study population, most patients (34 patients; 61.82%) demonstrated good adherence based on their knowledge level. Additionally, the majority of patients (41 patients; 74.55%) reported experiencing mild side effects, and most patients (24 patients; 43.64%) received good family support during their treatment. The majority of patients (50 patients; 90.91%) were categorized as adherent while undergoing antiretroviral treatment.

Table 3 presents a detailed investigation of family support parameters based on each component. Results indicate that for the instrumental and informational components, the majority of patients fell into the low category, comprising 45.45% and 40% of patients, respectively. In the assessment component, most patients were equally distributed in good and low categories, each comprising 38.18% of patients. Regarding the emotional component, most patients fell into good category, accounting for 50.91% of patients.

Table 2. Distribution of knowledge level, side effect severity, family support, and patient compliance.

Parameter	Frequency (n)	Percentage (%)
Knowledge Level		
Low	1	1.82
Moderate	20	36.36
Good	34	61.82
Total	**55**	**100.00**
Side Effect Severity		
No side effects	4	7.27
Mild	41	74.55
Moderate	8	14.54
Severe	2	3.64
Total	**55**	**100.00**
Family Support		
Low	19	34.54
Moderate	12	21.82
Good	24	43.64
Total	**55**	**100.00**
Adherence		
Non-adherent	0	0
Moderately adherent	5	9.09
Adherent	50	90.91
Total	**55**	**100.00**

Table 3. Description of family support by component.

Component of Support	Frequency Category			Total (Percentage, %)
	Good (Percentage, %)	Adequate (Percentage, %)	Low (Percentage, %)	
Instrumental	17 (30.91)	13 (23.64)	25 (45.45)	55 (100.00)
Assessment	21 (38.18)	13 (23.64)	21 (38.18)	55 (100.00)
Informational	19 (34.55)	14 (25.45)	22 (40.00)	55 (100.00)
Emotional	28 (50.91)	9 (16.36)	18 (32.73)	55 (100.00)

Table 4 shows the results of the Spearman correlation test, indicating no significant correlation between knowledge level, severity of ART side effects, and patient adherence to ART ($p = 0.959$; $p = 0.719$, respectively). However, although the correlation strength is weak, there was a statistically significant correlation between family support and patient compliance ($p = 0.004$; $r = 0.385$), indicating that patients who received better family support were more likely to comply with ART treatment, and vice versa.

Table 4. Spearman correlation test results.

Parameter	r	p	n
Knowledge level vs. patient adherence	0.007	0.959	55
Side effect severity vs. patient adherence	0.050	0.719	55
Family support vs. patient adherence	0.385	0.004*	55

Note: * p-value < 0.05 indicates a statistically significant correlation.

Discussion

Malang Islamic Hospital was selected as the research site because the hospital is equipped with a VCT polyclinic that specializes in providing care for HIV/AIDS cases. Additionally, the hospital provides comprehensive assistance to people living with HIV/AIDS (PLWHA), including those who have recently been diagnosed or have been undergoing ART treatment for an extended period. The study also involved the Netral Plus Indonesia Foundation, a peer support group community for PLWHA in the greater Malang area. The majority of patients in the study were from Malang City, comprising 56.36% of the sample.

Regarding patient demographics, the majority fell into the adult age category (80%) with an age range of 19–44 years. Previous research by Shiferaw et al. (2014) suggests that the lack of parental supervision during the transition from adolescence to adulthood can lead to risky sexual behavior by testing the limits of their newfound freedom through sexual experimentation, including experimentation with multiple sexual partners, inconsistent condom use, and engaging in sexual activity while under the influence of alcohol or narcotics (Shiferaw et al. 2014).

The majority of patients in this study were men (76.36%). According to data from the Data and Information Center of the Ministry of Health of the Republic of Indonesia (2020), Men who have Sex with Men (MSM) are considered a high-risk population for HIV infection, with a high number of new HIV cases (Data and Information Center of the Ministry of Health of the Republic of Indonesia 2020). MSM are particularly vulnerable to HIV infection through unprotected anal intercourse, as well as other risky behaviors such as consuming alcohol and using narcotics and illegal drugs. It further increases the risk of HIV infection. In India, nearly 50% of MSM are bisexual, meaning they have both male and female partners; this makes them a critical population in bridging HIV transmission to the general population (Kumar et al. 2020).

Regarding the ART regimen, the most common treatment (54.55%) received by patients in this study was Tenofovir disoproxil fumarate 300 mg + Lamivudine 300 mg + Efavirenz 600 mg (TLE). The combination of Tenofovir + Lamivudine (or Emtricitabine) + Efavirenz is a widely used first-line therapy for HIV treatment, recommended for both children aged five years and over and adults, including patients who are pregnant, nursing, have hepatitis B co-infection, or tuberculosis co-infection. These ART combinations are available in fixed-dose combination (FDC) forms. First-line therapy regimens are widely used because they are easier to use, more comfortable, and less toxic than second-line ART regimens. Studies have shown that early death, toxicity, and drug resistance are common in second-line ART, and one reason for the continued widespread use of first-line ART is the absence of indications of therapy failure (Ministry of Health of the Republic of Indonesia 2015; Mulisa et al. 2019).

In this study, knowledge level regarding HIV disease and its mode of transmission among PLWHA was measured using the KQ-HIV-18 questionnaire. The results of this study indicate that most patients (61.82%) had a good level of knowledge. Lack of knowledge about HIV transmission and prevention is a risk factor for the spread of the epidemic among young people (Lima et al. 2020). However, having good knowledge does not guarantee that a person will not engage in risky activities that can lead to HIV exposure.

The answers of the questionnaire on the side effects of ART treatment showed that most patients experienced a mild degree of severity (74.55%). Side effects of ART treatment are of the main reasons why PLWHA delay or discontinue ART. Therefore, clinical intervention is essential to help patients manage the side effects of ART. These side effects can reinforce negative attitudes toward ART treatment and lower patient adherence (Chen et al. 2013). Side effects often occur early in treatment, at intervals of two weeks, include rash, hepatotoxicity, gastrointestinal complaints, and central nervous system disturbances (Teklay et al. 2013).

The family support questionnaire results provide insight into the distribution of support received by patients from their families. Family support is divided into four components, namely instrumental, appraisal, informational, and emotional support. Instrumental support involves the provision of tangible assistance in the form of financial assistance, goods, labor, time, or direct assistance (Khamarko and Myers 2013). In this study, a majority of patients (45.45%) did not receive sufficient instrumental support, indicating that the patients did not receive material support in the form of funding or were never accompanied by their families in conducting consultations or being taken for treatment to health services.

Assessment support involves aiding in decision-making, offering appropriate feedback, and helping to determine which actions to take. It can also come in the form of encouragement, motivation, and assistance during the treatment period, which can increase PLWHA adherence to the ART regimen (Barik et al. 2020). In this study, it can be concluded that the assessment support received by patients is diverse.

Informational support refers to the provision of information, education, or guidance to help manage personal and health-related issues (Khamarko and Myers 2013). This study found that 40% of patients received insufficient informational support, indicating that the family's role in providing information and understanding about the disease and treatment is inadequate. This could be due to the lack of public discourse on issues related to HIV/AIDS and sexuality. This is inseparable from the notion that the discussion is sensitive or is still considered taboo in society (Aggleton et al. 2005).

The level of emotional support provided by both the patient's family and health workers can significantly impact their motivation to adhere to and complete the treatment regimen. Emotional support may manifest as empathy, compassion, and concern (Barik et al. 2020). Based on this study, it was found that most patients (50.91%) received adequate emotional support, indicating that families have a crucial role in providing patients with comfort, motivation, attention, and sympathy.

Furthermore, this study revealed that the majority of patients (43.64%) received good family support during their ART treatment. The results of this study are in line with research conducted by Kumala et al. (2022) in the Ceria Peer Support Group in Subang City, as many as 31 respondents (77.5%) received support from their families (Kumala et al. 2022).

The primary objectives of ART treatment are to extend and enhance the quality of life, prevent viral load escalation, and decrease the transmission of HIV. Achieving these objectives requires HIV/AIDS patients to maintain more than 95% adherence to ART treatment. Adherence to ART can increase CD4+ levels, decrease the progression of AIDS, and reduce mortality rates (Basti et al. 2017). CD4+ cells are a critical part of the immune system that signify improved immunity in HIV/AIDS patients (Yunita et al. 2020). However, four main obstacles in increasing ART adherence are (1) individual patient factors, including age, gender, education level, and knowledge about medication, (2) family support factors, (3) therapy regimen factors, and (4) health insurance factors (Debby et al. 2019).

According to the analysis results between knowledge level and compliance of PLWHA in undergoing ART treatment, there was no correlation between the two ($p = 0.959$). Knowledge is a critical component in shaping one's behavior, so the behavior formed will be better than behavior that is not based on knowledge. Good knowledge can serve as the foundation for PLWHA in motivating themselves to comply with the ART treatment they are undergoing (Potchoo et al. 2010). However, adherence is not only influenced by knowledge level since other factors such as individual awareness, self-motivation, busyness (especially for working people), intolerance to side effects, and a tendency to neglect medication when supplies run out may also influence adherence (Wulandari and Rukmi 2021). The findings of this study align with the research conducted by Aresta and Jumaiyah (2019) and Wulandari and Rukmi (2021), both of which suggest no statistically significant relationship between the level of knowledge and adherence to ART treatment, with p-values of 0.079 and 0.153, respectively (Aresta and Jumaiyah 2019; Wulandari and Rukmi 2021).

The study results revealed no correlation between the severity of side effects caused by ART treatment and PLWHA compliance ($p = 0.719$). These findings are consistent with the studies conducted by Pariaribo et al. (2017) with a p-value of 0.810 and Sari et al. (2021) with a p-value of 0.567, that there is no statistically significant relationship between the occurrence of side effects and adherence to ART treatment (Pariaribo et al. 2017; Sari et al 2021). Before starting therapy, PLWHA must receive accurate and adequate information and counseling on ART treatment (Kasumu and Alogun 2014). However, due to limited consultation time, doctors typically provide only the medical aspects and a brief explanation. Therefore, the role of peer mentors and counselors is crucial in providing information on the intricacies of ART treatment, particularly the risks of side effects or unwanted effects and how to manage if these adverse effects arise. In addition, pharmacists also play a critical role in preventing the development of ART resistance. They ensure the selection of appropriate ART therapy regimens, monitor and improve

PLWHA adherence, screen and manage drug interactions, anticipate and effectively manage therapy side effects, educate patients on the relation between non-adherence and antiretroviral therapy resistance, and manage treatment failure by suggesting a change in therapy to prevent further resistance (Tseng et al. 2012).

Further, the results of the correlation test of family support and patient adherence in undergoing ART treatment indicated a statistically significant relationship ($p = 0.004$). Healthcare providers should recognize the significant role of family support in shaping patient adherence to ART treatment. Therefore, it is essential to consider strategies that enhance positive family support while minimizing negative family interactions in order to increase patient compliance (Poudel et al. 2015).

Treatment compliance refers to the degree to which a patient's behavior in undergoing treatment adheres to the recommended treatment plan by health workers. High adherence to ART treatment is urgently needed to improve clinical and immunological conditions, reduce the risk of developing ART resistance, suppress viral replication, and reduce HIV transmission (Ministry of Health of the Republic of Indonesia 2019). For PLWHA whose families are aware of their HIV status, family support can be a crucial factor in increasing medication adherence. Family members can provide supervision and encouragement to PLWHA, serving as a Medication Supervisor for PLWHA. However, on the other hand, family conditions can also be a factor inhibiting adherence as PLWHA often miss ART doses for fear of being identified as HIV-positive (Afolabi et al. 2013).

Several efforts need to be made so that PLWHA can take antiretroviral therapy regularly, for example by providing counseling, including information regarding side effects, resistance, and benefits of treatment as well as education for families. This is intended to monitor adherence to taking medication and provide encouragement, motivation, and as a reminder to take antiretroviral therapy. In addition to counseling and education, medical personnel and the government must work together to ensure the affordability of ART treatment, as economic barriers often lead to patient non-adherence in undergoing therapy. It is crucial to note that ART treatment is lifelong (Putra et al. 2021).

Conclusions

This study concluded that there was no correlation between knowledge level, side effects, and adherence to ART treatment in PLWHA in Greater Malang. However, a statistically significant correlation was found between family support and adherence to ART treatment.

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References

Afolabi B, Afolabi M, Afolabi A, Odewale M, Olowookere S (2013) Roles of family dynamics on adherence to highly active antiretroviral therapy among people living with HIV/AIDS at a tertiary hospital in Osogbo, South-West Nigeria. African Health Sciences 13(4): 920–926. https://doi.org/10.4314/ahs.v13i4.9

Aggleton P, Wood K, Malcolm A, Parker R (2005) HIV–Related Stigma, Discrimination and Human Rights Violations: Case Studies of Successful Programmes. Joint United Nations Programme on HIV/AIDS (UNAIDS).

Aresta AS, Jumaiyah W (2019) Pengetahuan dan dukungan keluarga dengan kepatuhan dalam menjalankan pengobatan antiretroviral (ARV) pada pasien HIV/AIDS (Knowledge and family support in adherence to antiretroviral treatment (ARV) in HIV/AIDS patients). Indonesian Journal of Nursing Science and Practice 2(2): 51–61.

Arifin B, Rokhman MR, Zulkarnain Z, Perwitasari DA, Manggau M, Rauf S, Noor R, Padmawati RS, Postma MJ, Massi MN, Schans J (2022) Adaptation and validation of the HIV Knowledge Questionnaire-18 for the general population of Indonesia. Health and Quality of Life Outcomes 20(55): 1–12. https://doi.org/10.1186/s12955-022-01963-5

Aryanto SD, Rahmat I, Kustanti A (2018) Knowledge with nurse's stigma related to PLWHA. Jurnal Persatuan Perawat Nasional Indonesia 03(02): 98–110. https://doi.org/10.32419/jppni.v3i2.107

Barik AL, Indarwati R, Sulistiawati S (2020) The role of social support on treatment adherence in TB patients: a systematic review. Nurse and Health: Jurnal Keperawatan 9(2): 201–210. https://doi.org/10.36720/nhjk.v9i2.186

Basti BD, Mahesh V, Bant DD, Bathija GV (2017) Factors affecting antiretroviral treatment adherence among people living with human immunodeficiency virus/acquired immunodeficiency syndrome: a prospective study. Journal of Family Medicine and Primary Care 6(3): 482–486. https://doi.org/10.4103/2249-4863.222014

Bijker R, Jiamsakul A, Kityo C, Kiertiburanakul S, Siwale M, Phanuphak P, Akanmu S, Chaiwarith R, Wit FW, Sim BLH, Boender TS, Ditangco R, Wit TFRD, Sohn AH, Hamers RL (2017) Adherence to antiretroviral therapy for HIV in sub-Saharan Africa and Asia: a comparative analysis of two regional cohorts. Journal of the International AIDS Society 20(21218): 1–10. https://doi.org/10.7448/IAS.20.1.21218

Chatha ZF, Rashid U, Olsen S, Din F ud, Khan A, Nawaz K, Gan SH, Khan GM (2020) Pharmacist-led counselling intervention to improve antiretroviral drug adherence in Pakistan: a randomized controlled trial. BMC Infectious Diseases 20(874): 1–10. https://doi.org/10.1186/s12879-020-05571-w

Chen W, Shiu C, Yang JP, Simoni JM, Fredriksen-Goldsen KI, Lee TS, Zhao H (2013) Antiretroviral therapy (ART) side effect impacted on quality of life, and depressive symptomatology: a mixed-method

study. Journal of AIDS and Clinical Research 4(6): 1–8. https://doi.org/10.4172/2155-6113.1000218

Dahlan MS (2019) Besar Sampel dalam Penelitian Kedokteran dan Kesehatan Edisi ke-5 (Sample Size in Medical and Health Research 5th Edition). Epidemiologi Indonesia.

Debby C, Sianturi SR, Susilo WH (2019) Factors related to compliance of ARV medication in HIV patients at RSCM Jakarta. Jurnal Keperawatan 10(1): 15–25. https://doi.org/10.22219/jk.v10i1.5886

East Java Provincial Health Office (2021) East Java Provincial Health Profile 2020. East Java Provincial Health Office.

Hansana V, Sanchaisuriya P, Durham J, Sychareun V, Chaleunvong K, Boonyaleepun S, Schelp FP (2013) Adherence to Antiretroviral Therapy (ART) among People Living With HIV (PLHIV): a cross-sectional survey to measure in Lao PDR. BMC Public Health 13(617): 1–11. https://doi.org/10.1186/1471-2458-13-617

Jusriana J, Gobel FA, Arman A (2020) Faktor yang Mempengaruhi Kepatuhan Terapi Antiretrovial pada Orang dengan HIV di Yayasan Peduli Kelompok Dukungan Sebaya Kota Makassar (Factors related to antiretroviral therapy adherence in people living with HIV at the Peer Support Group Care Foundation in Makassar City). Window of Public Health Journal 1(3): 241–249. https://doi.org/10.33096/woph.v1i3.56

Justice AC, Holmes W, Gifford AL, Rabeneck L, Zackin R, Sinclair G, Weissman S, Neidig J, Marcus C, Chesney M, Cohn SE, Wu AW (2001) Development and validation of a self-completed HIV symptom index. Journal of Clinical Epidemiology 54(2001): S77–S90. https://doi.org/10.1016/S0895-4356(01)00449-8

Kasumu B, Alogun M (2014) Knowledge and attitude towards antiretroviral therapy and adherence pattern of HIV patients in southwest Nigeria. International Journal of Infection Control 10(i3): 1–8.

Khamarko K, Myers JJ (2013) The Influence of Social Support on the Lives of HIV-Infected Individuals in Low- and Middle-Income Countries. World Health Organization.

Kumala TF, Lindayani L, Hasan A, Ropei O, Badrujamalludin A, Sudrajat DA (2022) Family support for HIV patients undergoing antiretroviral therapy in Subang City, The International Virtual Confrence on Nursing Knowledge E (KnE) Life Science Volume 2022. Bandung: STIKep PPNI Jawa Barat and National Cheng Kung. https://doi.org/10.18502/kls.v7i2.10331

Kumar P, Aridoss S, Mathiyazhakan M, Balasubramanian G, Jaganathasamy N, Natesan M, Padmapriya VM, David JK, Rajan S, Adhikary R, Arumugam E (2020) Substance use and risk of HIV infection among Men who have Sex with Men in India. Medicine 99(35): 1–8. https://doi.org/10.1097/MD.0000000000021360

Lima MS, Raniere JC, Paes CJO, Gonçalves LHT, Cunha CLF, Ferreira GRON, Botelho EP (2020) The association between knowledge about HIV and risk factors in young Amazon people. Revista Brasileira de Enfermagem 73(5): 1–8. https://doi.org/10.1590/0034-7167-2019-0453

Mardalena SA (2020) Building anti-Acquired Immune Deficiency Syndrome (AIDS) – Human Immunodeficiency Virus (HIV) behavior in adolescent groups. Jurnal BERDIKARI 8(1): 41–7. https://doi.org/10.18196/bdr.8175

Merati TP, Karyana M, Tjitra E, Kosasih H, Aman AT, Alisjahbana B, Lokida D, Arlinda D, Maldarelli F, Neal A, Arif M, Gasem MH, Lukman N, Sudarmono P, Lau C, Hadi U, Lisdawati V, Wulan WN, Lane HC, Siddiqui S (2021) Prevalence of HIV infection and resistance mutations in patients hospitalized for febrile illness in Indonesia. American Journal of Tropical Medicine and Hygiene 105(4): 960–965. https://doi.org/10.4269/ajtmh.20-1595

Ministry of Health of the Republic of Indonesia (2015) Regulation of the Minister of Health of the Republic of Indonesia Number 87 of 2014 concerning Guidelines for Antiretroviral Treatment. Ministry of Health of the Republic of Indonesia.

Ministry of Health of the Republic of Indonesia (2019) Decree of the Minister of Health of the Republic of Indonesia Number HK.01.07/MENKES/90/2019 concerning National Medical Service Guidelines for HIV Management. Ministry of Health of the Republic of Indonesia.

Mulisa D, Tesfa M, Kassa GM, Tolossa T (2019) Determinants of first line antiretroviral therapy treatment failure among adult patients on ART at central Ethiopia: un-matched case control study. BMC Infectious Diseases 19(1024): 1–13. https://doi.org/10.1186/s12879-019-4651-6

Nadia R, Elvira D, Raveinal R (2022) HIV drug resistance mutations. Bioscientia Medicina 6(7): 2006–2013. https://doi.org/10.37275/bsm.v6i7.547

Panel on Antiretroviral Guidelines for Adults and Adolescents (2022) Guidelines for the Use of Antiretroviral Agents in Adults and Adolescents with HIV. The Office of AIDS Research Advisory Council (OARAC).

Pariaribo K, Hadisaputro S, Widjanarko B, Sofro MAU, Adi S (2017) Faktor risiko yang mempengaruhi kepatuhaan terapi antiretroviral (ARV) pada pasien HIV/AIDS di RSUD Abepura Jayapura (Risk factors influencing adherence to antiretroviral therapy (ARV) in HIV/AIDS patients at Abepura Regional General Hospital, Jayapura). Jurnal Epidemiologi Kesehatan Komunitas 2(1): 7–16. https://doi.org/10.14710/jekk.v2i1.3966

Potchoo Y, Tchamdja K, Balogou A, Pitche VP, Guissou IP, Kassang EK (2010) Knowledge and adherence to antiretroviral therapy among adult people living with HIV/AIDS treated in the health care centers of the association "Espoir Vie Togo" in Togo, West Africa. BMC Clinical Pharmacology 10(11): 1–7. https://doi.org/10.1186/1472-6904-10-11

Poudel K, Buchanan D, Amiya R, Poudel-Tandukar K (2015) Perceived family support and antiretroviral adherence in HIV-positive individuals: results from a community-based positive living with HIV study. International Quarterly of Community Health Education 36(1): 71–91. https://doi.org/10.1177/0272684X15614220

Putra DS, Atmadani RN, Hidayati IR (2021) Relationship between knowledge level of HIV/AIDS patient with antiretroviral adherence in primary healthcare service in Malang City. Journal of HIV/AIDS & Social Services 20(3): 1–18. https://doi.org/10.1080/15381501.2021.1961651

Roslandari LMW, Illahi RK, Lawuningtyas A (2020) The relationship between family support and the level of adherence to treatment of hypertensive outpatients in the chronic disease management program. Pharmaceutical Journal of Indonesia 5(2): 131–139. https://doi.org/10.21776/ub.pji.2020.005.02.10

Sari AM, Hidayati IR, Atmadani RN (2021) Hubungan tingkat efek samping obat ARV pada pasien ODHA terhadap tingkat kepatuhan penggunaan obat ARV (Correlation between ARV drug side effect level in PLWHA patients and adherence level to ARV medication). Pharmaceutical Journal of Indonesia 6(2): 117–120.

Shiferaw Y, Alemu A, Assefa A, Tesfaye B, Gibermedhin E, Amare M (2014) Perception of risk of HIV and sexual risk behaviors among university students: implication for planning interventions. BMC Research Notes 7(162): 1–8. https://doi.org/10.1186/1756-0500-7-162

Srikartika VM, Intannia D, Aulia R (2019) Factors influencing HIV/AIDS outpatients adherence to antiretroviral therapy (ART) at Dr. H. Moch. Ansari Saleh hospital Banjarmasin. Jurnal Pharmascience 06(01): 97–105. https://doi.org/10.20527/jps.v6i1.6081

Teklay G, Legesse B, Legesse M (2013) Adverse effects and regimen switch among patients on antiretroviral treatment in a resource limited setting in Ethiopia. Journal of Pharmacovigilance 1(4): 1–5. https://doi.org/10.4172/2329-6887.1000115

Thompson K, Kulkarni J, Sergejew AA (2000) Reliability and validity of a new Medication Adherence Rating Scale (MARS) for the psychoses. Schizophrenia Research 42(2000): 241–247. https://doi.org/10.1016/S0920-9964(99)00130-9

Tseng A, Foisy M, Hughes CA, Kelly D, Chan S, Dayneka N, Giguère P, Higgins N, Hills-Nieminen C, Kapler J, Porte CJ, Nickel P, Park-Wyllie L, Quaia C, Robinson L, Sheehan N, Stone A, Sulz L, Yoong D (2012) Role of the pharmacist in caring for patients with HIV/AIDS: clinical practice guidelines. Canadian Journal of Hospital Pharmacy 65(2): 125–145. https://doi.org/10.4212/cjhp.v65i2.1120

Tyastirin E, Hidayati I (2017) Statistik Parametrik untuk Penelitian Kesehatan (Parametric Statistics for Health Research). Program Studi Arsitektur UIN Sunan Ampel.

Wulandari EA, Rukmi DK (2021) The correlation between the level of knowledge and the adherence on ARV therapy of ODHA in Yogyakarta. Clinical and Community Nursing Journal 5(3): 157–166. https://doi.org/10.22146/jkkk.49663

Yunita EP, Winarsih S, Deasury NR (2020) The long-term effect of using ARV combinations (TDF+3TC+EFV) on CD4+ cell counts of HIV/AIDS patients. Indonesian Journal of Clinical Pharmacy 9(3): 219–228. https://doi.org/10.15416/ijcp.2020.9.3.219

Appendix 1. Questionnaire on Patient Identity, Type of ART, and Frequency of Use

1. Inisial Nama :
2. Domisili : Kota Malang/Kabupaten Malang/Kota Batu
3. Usia :
4. Jenis kelamin : L/P
5. No. Telepon :
   (digunakan untuk pengisian saldo OVO/GoPay/Shopeepay/Pulsa/DANA)
6. Jenis ARV :

Petunjuk :

Berilah tanda contreng (✓) pada jenis ARV yang Bapak/Ibu/Saudara gunakan dan isilah titik-titik dibawah sesuai dengan frekuensi penggunaan ARV Bapak/Ibu/Saudara.

☐ Efavirenz 600 mg, … kali sehari.
☐ Nevirapine 200 mg, … kali sehari.
☐ Rilpivirin 25 mg, … kali sehari.
☐ Dolutegravir 50 mg, … kali sehari.
☐ Tenofovir 300 mg, … kali sehari.
☐ Zidovudin 600 mg, … kali sehari.
☐ Lamivudin 150 mg, … kali sehari.
☐ Emtricitabine 200 mg, … kali sehari.
☐ Abacavir 300 mg, … kali sehari.
☐ Lopinavir 200 mg + Ritonavir 50 mg, … kali sehari.
☐ Lamivudine 150 mg + Zidovudine 300 mg, … kali sehari.
☐ Tenovofir 300 mg + Emtricitabine 200 mg, … kali sehari.
☐ Tenovofir Disoproxil Fumarate 300 mg + Lamivudine 300 mg + Efavirenz 600 mg, … kali sehari.
☐ Dolutegravir Sodium 50 mg + Lamivudine 300 mg + Tenovofir Disoproxil Fumarate 300 mg, … kali sehari.
☐ Lain-lainnya: … , … kali sehari.

Appendix 2. Questionnaire on Knowledge Level

Table A1. Berilah tanda contreng (✓) pada pernyataan yang menurut Bapak/Ibu/Saudara paling sesuai!

No.	Pernyataan	Benar	Salah	Tidak Tahu
1.	Batuk dan bersin tidak menyebarkan HIV.			
2.	Seseorang dapat tertular HIV jika ia berbagi segelas air dengan seseorang yang positif menderita HIV.			
3.	Menarik penis sebelum seorang pria mencapai klimaks/orgasme (sebelum mengeluarkan sperma); akan dapat mencegah seorang wanita terkena HIV selama berhubungan seks.			
4.	Seorang wanita dapat tertular HIV jika dia melakukan hubungan seks anal (melalui dubur/anus) dengan seorang pria.			
5.	Mandi atau mencuci alat kelamin/ bagian pribadi seseorang, setelah berhubungan seks dapat mencegah seseorang tertular HIV.			
6.	Seorang wanita hamil penderita HIV, dapat menularkan penyakitnya kepada janin yang sedang dikandungnya. Hal ini berdampak pada bayi yang lahir akan menderita HIV seumur hidup.			
7.	Orang yang telah terinfeksi HIV dengan cepat menunjukkan tanda-tanda serius sudah terinfeksi. Tanda-tanda serius ini, akan muncul maksimal 5 (lima) hari setelah terinfeksi.			
8.	Saat ini, sudah tersedia vaksin yang dapat mencegah orang dewasa dari terkena HIV.			
9.	Orang-orang cenderung tertular HIV melalui ciuman yang dalam yaitu dengan menjulurkan lidah ke mulut pasangannya yang terkena HIV.			
10.	Seorang wanita yang sedang menstruasi, tidak dapat tertular HIV jika dia berhubungan seks.			
11.	Saat ini, sudah ada kondom untuk wanita yang dapat membantu mengurangi peluang wanita terkena HIV.			
12.	Kondom berbahan kulit alami (yang terbuat dari kulit domba atau lambskin) berfungsi lebih baik dalam melawan HIV dibandingkan dengan kondom berbahan karet.			
13.	Seseorang tidak akan tertular HIV selama dia menggunakan antibiotik. Contoh antibiotik: ampisilin, amoksisilin, dan lain sebagainya.			
14.	Berhubungan seks dengan lebih dari satu pasangan (seks bebas) dapat meningkatkan risiko seseorang terinfeksi HIV.			
15.	Melakukan tes HIV satu minggu setelah berhubungan seks dapat memberi tahu seseorang apakah dia terinfeksi HIV atau tidak.			
16.	Seseorang dapat tertular HIV dengan duduk bersama dalam satu bak mandi air panas atau menggunakan kolam renang bersama dengan orang yang menderita HIV.			
17.	Seseorang bisa tertular HIV bila ia melakukan seks oral (seks dengan menggunakan mulut).			
18.	Menggunakan vaseline atau ***baby oil*** bersama dengan kondom menurunkan kemungkinan terkena HIV.			

(Arifin et al. 2022).

Appendix 3. Questionnaire on Side Effects

Table A2. Pertanyaan-pertanyaan berikut menanyakan tentang gejala-gejala yang mungkin Bapak/Ibu/Saudara alami dalam empat minggu terakhir. Berilah tanda contreng (✓) pada pernyataan yang mendeskripsikan seberapa jauh Bapak/Ibu/Saudara terganggu dengan setiap gejala.

No.	Pertanyaan	Saya tidak memiliki gejala ini	Saya Memiliki Gejala Ini dan...			
			Tidak terganggu	Sedikit terganggu	Cukup terganggu	Sangat terganggu
1.	Kelelahan atau kehilangan energi?					
2.	Demam, kedinginan (menggigil), atau berkeringat?					
3.	Merasa pusing (pening) atau kepala berputar?					
4.	Sakit, mati rasa, atau kesemutan (kebas) di tangan atau kaki?					
5.	Kesulitan mengingat?					
6.	Mual atau muntah?					
7.	Diare atau feses encer?					
8.	Merasa sedih, murung, atau depresi?					
9.	Merasa gugup atau cemas?					
10.	Kesulitan tidur atau kesulitan tidur nyenyak?					
11.	Masalah kulit, seperti ruam, kulit kering, atau gatal?					
12.	Batuk atau sesak napas?					
13.	Sakit kepala?					
14.	Kehilangan selera makan (nafsu makan) atau perubahan dalam rasa makanan (contoh: terasa pahit, hambar, atau logam)?					
15.	Kembung, nyeri ulu hati, atau kentut?					
16.	Nyeri otot atau nyeri sendi?					
17.	Masalah dalam hubungan seksual, seperti hilang ketertarikan atau kurang kepuasan?					
18.	Peningkatan berat badan?					
19.	Penurunan berat badan?					
20.	Rambut rontok atau kebotakan?					

(Justice et al. 2001).

Appendix 4. Questionnaire on Family Support

Table A3. Berilah tanda contreng (✓) pada pernyataan yang menurut Bapak/Ibu/Saudara paling sesuai!

No.	Pernyataan	Selalu	Sering	Kadang-Kadang	Tidak Pernah
1.	Keluarga saya mengusahakan dana yang diperlukan untuk biaya pengobatan dan perawatan saya.				
2.	Keluarga memperhatikan setiap jenis makanan yang saya konsumsi.				
3.	Keluarga berusaha menyediakan obat-obatan yang saya butuhkan.				
4.	Keluarga menganjurkan saya untuk minum obat secara teratur.				
5.	Keluarga saya mempunyai cukup waktu untuk menemani saya berobat atau kontrol.				
6.	Keluarga saya memberikan pujian ketika saya menjalankan pengobatan dengan sungguh-sungguh.				
7.	Keluarga saya membantu memecahkan setiap masalah dan kendala dalam menjalankan pengobatan.				
8.	Ketika saya sakit, keluarga menganggap saya seperti sebelum saya sakit dan tidak menjadi beban dalam keluarga.				
9.	Keluarga saya mengingatkan saya untuk mematuhi anjuran dokter dan perawat (petugas kesehatan).				
10.	Keluarga saya tanggap terhadap setiap masalah yang saya alami selama di rumah.				
11.	Keluarga mencari informasi tentang upaya penyembuhan untuk penyakit yang saya alami.				
12.	Keluarga saya memberikan informasi tentang akibat apabila tidak patuh minum obat.				
13.	Keluarga saya mengingatkan tentang hal-hal yang harus dihindari selama menjalankan pengobatan seperti tidak merokok, tidak minum alkohol, mengurangi makanan berlemak, atau mengurangi konsumsi garam.				
14.	Selama sakit, saya mendapat dukungan atau saran dari keluarga dalam penggunaan obat jangka panjang.				
15.	Keluarga mengingatkan saya untuk menjaga pola hidup sehat seperti makan sayur, buah, berolahraga minimal 30 menit (jalan santai, senam, joging, bersepeda, atau berenang).				
16.	Perhatian dan dukungan dari keluarga membuat saya termotivasi untuk menjalankan pengobatan dengan sungguh-sungguh.				
17.	Kedekatan dan kehangatan dalam keluarga membuat saya merasa dicintai dan disayangi sehingga saya merasa tenang dan termotivasi dalam menjalankan pengobatan saya.				
18.	Keluarga saya mendengarkan apa yang menjadi keluh kesah saya selama menjalani pengobatan.				
19.	Keluarga memberikan semangat dan dukungan ketika saya malas mengikuti pengobatan saya.				
20.	Nasihat dari keluarga memotivasi saya untuk patuh dalam pengobatan.				

(Roslandari et al. 2020).

Appendix 5. Questionnaire on Adherence Level

Table A4. Jawablah pertanyaan-pertanyaan berikut dengan memberi tanda contreng (✓) pada jawaban yang paling sesuai dengan perilaku Bapak/Ibu/Saudara terhadap pengobatan ART dalam satu minggu terakhir.

No.	Pernyataan	Ya	Tidak
1.	Apakah Bapak/Ibu/Saudara pernah lupa minum obat?		
2.	Apakah Bapak/Ibu/Saudara kadang meminum obat tidak sesuai dengan petunjuk minum obat (waktu, dosis, atau frekuensi) yang telah diberikan?		
3.	Ketika Bapak/Ibu/Saudara merasa lebih baik/sehat, apakah Bapak/Ibu/Saudara berhenti minum obat sesuai dengan anjuran?		
4.	Ketika Bapak/Ibu/Saudara merasa lebih buruk/sakit setelah meminum obat, apakah Bapak/Ibu/Saudara berhenti minum obat sesuai dengan anjuran?		
5.	Saya minum obat hanya ketika saya merasa sakit saja.		
6.	Saya merasa dengan meminum obat dapat membuat saya ketergantungan.		
7.	Perasaan Bapak/Ibu/Saudara lebih baik apabila meminum obat.		
8.	Dengan meminum obat secara rutin, dapat mencegah saya terkena/terjangkit/tertular penyakit (misal: flu, Covid-19, pneumonia, tuberkulosis, hepatitis, infeksi jamur, diare kronis).		
9.	Saya merasa meminum obat dapat mengganggu aktivitas sehari-hari.		
10.	Meminum obat membuat saya merasa lelah dan lamban.		

(Thompson et al. 2000).