

Level of ability and adherence to antiretroviral therapy medication and quality of life for PLHIV

Misutarno Misutarno^{1,2}, Nursalam Nursalam^{1*}, Tintin Sukartini¹, Diah Priyantini³

¹Faculty of Nursing, Universitas Airlangga, Surabaya, Indonesia. ²Faculty of Health Sciences, Universitas Nahdlatul Ulama, Surabaya, Indonesia. ³Faculty of Health Sciences, Universitas Muhammadiyah Surabaya, Surabaya, Indonesia.

Corresponding author: Nursalam Nursalam (Email: nursalam@fkp.unair.ac.id)

Abstract

The quality of life of people with human immunodeficiency virus (PLHIV) is one of the concerns in the world of health that must be resolved so that health status continues to improve. This study aimed to analyze the correlation between the level of ability and adherence to antiretroviral therapy medication and the quality of life for PLHIV. A quantitative survey with a cross-sectional approach was conducted in the Tulungagung AIDS Eradication Commission, East Java, Indonesia. The study was conducted between October and December 2022 to evaluate the Ability Level, Compliance with ART Consumption, and Quality of Life of PLHIV. A total of 60 PLHIV were recruited and agreed to give consent as research respondents. All respondents who agreed to sign the informed consent to participate in this study were then asked to complete a questionnaire about Ability Level, Compliance with ART Consumption, and Quality of Life. Spearman's rho was used to detect the correlation between ability level, ART adherence, and quality of life. The results of cross-tabulation between the patient's level of ability, ART adherence, and quality of life among PLHIV show that patients whose level of ability is good demonstrate a higher quality of life (p = 0.005). Likewise, with patient ART compliance, the better the compliance, the higher the quality of life (p = 0.010).

Keywords: Ability, Adherence, Antiretroviral, PLHIV, Quality of Life.

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1. Introduction

The quality of life of people living with human immunodeficiency virus (PLHIV) is one of the concerns in the world of health that must be addressed, so that health status continues to improve [1]. Generally, PLHIV will experience psychological distress such as boredom, decreased enthusiasm, and even depression while undergoing treatment, due to the relatively long

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duration and the amount of therapy that PLHIV must receive [2]. Negative coping mechanisms during the treatment period can affect immunity status, leading many PLHIV with low immunity to experience Acquired Immunodeficiency Syndrome (AIDS) and opportunistic infections (OIs), which will impact the quality of life of PLHIV [3]. A progressive decrease in immunity can be triggered by non-compliance with the use of antiretrovirals (ARVs), causing the number of viruses in the sufferer's body to increase; as a result, the viral load will show a high number and the number of Cluster of Differentiation 4 (CD4) will decrease further [4]. Not only that, PLHIV are often faced with social stigma and discrimination, which can increase their psychological burden and level of ability to survive. This, of course, impacts the quality of life of PLHIV and can lead to isolation and withdrawal, as the quality of life of PLHIV encompasses not only physical health and psychological conditions but also the level of independence, social relations, and the relationship of PLHIV with their environment [5].

The prevalence of PLHIV throughout the world continues to increase; in 2019, it reached 38 million sufferers [6]. Indonesia is one of the countries in Southeast Asia with the highest number of HIV/AIDS cases, reaching 48,300 individuals living with HIV/AIDS. Of the large number of sufferers in the world, only 65% have access to antiretrovirals, whereas in Indonesia, compliance with Antiretroviral Therapy (ART) is still a major problem. This is evidenced by the level of Lost Follow Up (LFU) for treatment and antiretroviral therapy, which remains sufficiently high at 21.87%. [7]. East Java Province occupied the first position in Indonesia with the highest HIV incidence in 2017, followed by DKI Jakarta and Central Java. According to a report on HIV care and antiretroviral therapy in 2017, there were approximately 214,819 people who were eligible for antiretrovirals, but only 180,843 people received them. Of the 180,843 people who had received antiretroviral therapy, 39,542 people (21.87%) lost LFU follow-up (21.87%), and 3,501 (1.93%) stopped taking antiretrovirals. This decrease in adherence to antiretroviral therapy ultimately makes sufferers prone to opportunistic infections (OIs) and leads to a poor quality of life due to stigma and hopelessness. The prevalence of HIV patients who did not take antiretrovirals out of 1,603 patients was 123 patients (7.7%), resulting in opportunistic infections. Data on opportunistic infections indicate that the most common causes are bacterial pneumonia (25.8%), candidiasis (18.3%), pneumonia (11.9%), tuberculosis (11.5%), diarrhea (9.3%), cryptococcus (7.3%), and cytomegalovirus (4.9%) [8]. HIV patients with many opportunistic infections will have a worse quality of life (31.25%) compared to patients without symptoms or without opportunistic infections (11.11%) [9]. The study results show that the majority of PLHIV have negative coping mechanisms (60.0%), while a small percentage have positive coping mechanisms (40%) [10, 11].

The impact of non-adherence to ARV therapy can cause several problems, such as increasing viral load, drug resistance, decreasing the number of Cluster of Differentiation 4+ (CD4+), worsening objective health status, and decreasing subjective health status. The occurrence of resistance to the drugs given will result in increasingly limited choices of drugs that can be used by PLHIV in the future [12]. If this continues, it will result in ARV therapy for HIV/AIDS patients no longer having benefits, and the negative risk that will occur is an increase in virus transmission and the occurrence of severe opportunistic infections, which can even cause an increase in the death rate among HIV/AIDS patients. Factors that increase compliance with ARV therapy include the formation of good coping management in individuals through adaptability, as well as psychological and behavioral characteristics. PLHIV with good coping mechanisms tend to be less affected by negative stressors that arise as a response to the difficult conditions they experience. Higher resilience is significantly associated with a lower prevalence of depression in PLHIV [13, 14]. Psychosocial factors such as disease interpretation and emotional responses indirectly influence PLHIV's compliance with treatment and play a role in forming adaptive coping and individual resilience in responding to the stressors experienced. Adaptive coping mechanisms are characterized by an individual's ability to seek information and assistance in managing their illness. This will further improve the health behavior of PLHIV in treatment and produce the final outcome in the form of improved quality of life. Other factors, such as social support, family support, and support from health workers, are also considered to influence PLHIV's assessment of their illness and subsequently build resilience and increase compliance in treatment management [1, 13].

Efforts that can be made to solve complex problems in PLHIV are by improving self-management. The self-management process is closely related to the emotional management process. The emotional management process is broadly a person's process of managing all types of affective or emotional responses, namely attention, cognitive representation, and physical or behavioral responses. Self-management for PLHIV can help to motivate and direct their actions in achieving a goal of improving their quality of life. Several aspects of self-management are metacognition, motivation, and behavior. This aspect of self-management then provides direction and goals to be achieved as well as ways to achieve these goals. This theory is considered suitable to be integrated for PLHIV because it has the same goal, namely forming adaptive coping so that the ability to survive and adherence to ARVs will improve. This study aimed to analyze the correlation between the level of ability and adherence to antiretroviral therapy medication and quality of life for PLHIV.

2. Methods

2.1. Study Design and Setting

A quantitative survey with a cross-sectional approach was conducted in the Tulungagung AIDS Eradication Commission, East Java, Indonesia. The study was conducted between October and December 2022 to evaluate the ability level, compliance with ART consumption, and quality of life of PLHIV. The research location was chosen based on the relatively high level of HIV/AIDS prevalence in the Tulungagung Regency area, making it necessary to research the abilities of sufferers, ART compliance, and the quality of life of PLHIV.

2.2. Participants

A total of 60 PLHIV were recruited and agreed to give consent as research respondents. They were recruited according to the criteria: 1) Diagnosed as HIV positive by three methods of testing (oncoprobe, intake, and vikia); 2) Age between 20

and 55 years; 3) Taking ART for at least 6 months; 4) Able to read and write well; 5) Able to communicate effectively; 6) No mental illness; and 7) No visual or hearing impairment. Respondents who met the inclusion criteria were informed about the research procedure. Once the potential respondents agreed to participate in the research, they were asked to sign an informed consent form. All respondents agreed to sign the information form provided by the authors.

2.3. Data Collection

All respondents who agreed to sign the informed consent to participate in this study were then asked to complete a questionnaire about Ability Level, Compliance with ART Consumption, and Quality of Life. They completed the questionnaire in a special room that has been provided to maintain the privacy of PLHIV from other respondents. The questionnaire in this study includes socio-demographic characteristics which collect age, gender, marital status, ethnicity, religion, educational history, employment, and income [15]. ART adherence was identified based on two measures in the last week and the last three months. If they self-reported taking \geq 95% of ART medication in a 7-day period, they were categorized as adherent; if they missed \geq 1 dose of ART medication within this time period, they were categorized as anon-adherent. The second measurement describes if PLHIV taking ART medication routinely \geq 95% of 3 months, it was indicated as adherent, and if they missed \geq 3 doses of ART medication within this time period, they were determined as non-adherent [16, 17]. Respondents were assessed regarding their level of independence using a questionnaire that had been modified by the researcher. Quality of Life questionnaire used was WHOQOL-HIV BREF.

2.4. Data Analysis

Descriptive analysis was performed to provide an overview of socio-demographic characteristic data and specific variables of the percentage of ART adherence, level of ability, and quality of life of PLHIV. Spearman's rho was used to detect the correlation between ability level, ART adherence, and quality of life. The independent variable was ordinally coded (1 = Good, 2 = Intermediate, 3 = Bad), the dependent variable was coded as binary (1 = Adherent and 2 = Non-adherent), and the quality of life was coded ordinally (1 = Low, 2 = Intermediate, 3 = High). All analyses were performed using SPSS version 21 with a significance level of p < 0.05.

2.5. Ethical Consideration

Ethics approval for this study was assessed and obtained from the Health Research Ethics Commission, Faculty of Nursing, Airlangga University, with ethics certificate number 2582-KEPK. The researcher first provided an explanation of the research procedures to the research respondents and obtained informed consent by adhering to research ethical principles.

Respondent Characteristics	n	f (%)
Age		-
Late teens	9	15.00
Early adulthood	18	30.00
Late adulthood	22	36.67
Early seniors	8	13.33
Seniors	3	5.00
Gender		
Man	47	78.33
Woman	13	21.67
Marital status		
Single	28	46.67
Marry	28	46.67
Widower widow	4	6.67
Tribes		
Java	51	85.00
Buginese	1	1.67
Madurese	5	8.33
Sunda	3	5.00
Religion		
Islam	53	88.33
Catholic	2	3.33
Christian	4	6.67
Hindu	1	1.67
Work		
Doesn't work	20	33.33
Civil servants	1	1.67
Trader	8	13.33
Self-employed	23	38.33

Table 1. Characteristics of Research Respondents (n = 60)

Respondent Characteristics	n	f (%)
Farmer	2	3.33
Student	1	1.67
Housewife	2	3.33
Driver	3	5.00
Last education		
College	5	8.33
High School Equivalent	38	63.33
Middle School Equivalent	9	15.00
Elementary School Equivalent	6	10.00
No school	2	3.33
Disease History		
There is a disease	10	16.67
There isn't any	50	83.33
Patient's level of ability		
Good	25	41.67
Intermediate	20	33.33
Bad	15	25.00
ART Treatment Adherence		
Low	17	28.33
Intermediate	20	33.33
High	23	38.33
Quality of Life		
Low	16	26.67
Intermediate	20	33.33
High	24	40.00

Table 2.

Cross tabulation between Patient's level of ability, ART adherence and quality of life among PLHIV (n=60).

	Quality of life					Spearman rho test	
Independent Variable		Low		Intermediate		igh	
	f	%	f	%	f	%	
Patient's level of ability							0.005
Bad	1	1.7	8	13.3	1	1.7	
Intermediate	7	11.7	13	21.7	5	8.3	
Good	2	3.3	8	13.3	15	25.0	
ART Treatment Adherence							
Low	1	1.7	8	13.3	1	1.7	0.010
Intermediate	5	8.3	10	16.7	10	16.7	
High	0	0.0	9	15.0	16	26.7	

3. Results

The results showed that 36.67% of the 60 respondents were in early senior age, with the majority gender being male (78.33%). Marital status was balanced between those who were not married and those who were married, at 46.67%, and the majority came from Javanese ethnicity (85.00%). The largest religion is Islam (88.33%), 38.33% are self-employed, and 63.33% have last education at the high school graduate level. The condition of the patients' level of ability is mostly good at 41.67%, and there are also 25.00% showing bad. The low level of ART adherence was 28.33%. The level of quality of life for PLHIV is good, but there are 26.67% whose quality of life is low (Table 1). The results of cross-tabulation between patients' level of ability, ART adherence, and quality of life among PLHIV show that patients whose level of ability is good demonstrate a higher quality of life. Likewise, with patient ART compliance, the better the compliance, the higher the quality of life.

4. Discussion

Increasing the ability of PLHIV has a significant relationship with adherence to ARV treatment. This could be because PLHIV whose abilities have improved also show a positive response in themselves, so they will be more compliant with ARV treatment because PLHIV want to stay healthy. Increasing the abilities of PLHIV will also improve their capacity in terms of carrying out daily activities, practicing their beliefs in worship, determining abilities in coping mechanisms, engaging in social interactions, participating in worship activities, enhancing self-confidence, achieving social acceptance, practicing self-care, and managing feelings. If all of these aspects can be managed well, the lives of PLHIV will always be positive and will have an impact on ARV treatment compliance, including accuracy in schedules, accuracy in quantity, accuracy in type, management of side effects, acceptance of information, and motivation within PLHIV [4, 18].

ARV therapy is expected to reduce morbidity and mortality, improve quality of life, maintain immunity, and suppress viral replication as much as possible. Compliance or adherence is a condition where the patient follows his treatment based on his own awareness, not merely obeying the doctor's orders. Compliance is an important factor in the success of ARV therapy. The risk of therapy failure occurs if the patient often forgets to take medication. To achieve optimal therapeutic effects in suppressing viral replication, a compliance level of at least 95% is required. Good compliance involves taking medication as prescribed and agreed upon between the patient and the health worker. Poor compliance includes missing doses or using medication inappropriately (taking it at the wrong time or breaking certain dietary restrictions). A minimum compliance rate of 95% or greater is required to achieve and maintain an undetectable viral load. Viral suppression rates can reach 78-100% after six to ten months of therapy. On the other hand, sufferers who have a compliance level of <90% are likely to experience failure to suppress the amount of virus, although some sufferers with a much lower level of compliance sufferers do not show any detectable virus [6, 19].

Several studies state that supporting factors are social support, self-confidence that through treatment the quality of life will improve, a good relationship with a health care provider, and the role of a companion in taking medication. Patient compliance will influence logistics management planning for ARV drugs so that treatment-seeking behavior becomes an important factor for sufferers themselves and the success of the HIV-AIDS treatment program. Several factors supporting adherence to ARV medication in this study were self-motivation, support from family, support from friends, and support from the community. Social support from family, friends, and health workers has an important influence on PLHIV's adherence to taking ARVs. Self-motivation is the desire to survive and not want to get sick. Motivation from within PLWHA to recover or survive is the most frequently stated supporting factor for compliance by respondents. The main factor that influences the optimism in life of PLWHA is the sufferer's strong life motivation. With optimism in life, PLWHA have the enthusiasm to work, motivation to live, and positive thoughts [20, 21].

Factors causing low compliance with treatment for HIV/AIDS sufferers include fear of their status in society, lack of knowledge about the importance of regular medication, depression, distrust of medicines, forgetting to take medicines, and fear of side effects. Some of the barriers to adherence to ARV medication are the cost of treatment, side effects of the medication, and stigma. The treatment cost factors expressed by PLWHA were for transportation, administration, and blood tests (CD4), which, according to them, were quite expensive. Riyarto's research shows that the costs incurred due to HIV disease are greater when undergoing ARV therapy. Forty-five percent of the total respondents experienced catastrophic losses after undergoing treatment, causing poverty. This shows that even though ARV drugs have been provided free of charge by the government, the financial burden for treatment remains large. Side effects are often a medical reason to change or stop ARV therapy. Many PLHIV cannot tolerate the side effects of the drug, so they stop the therapy themselves. Side effects can occur at the start of treatment, such as anemia due to zidovudine, or in the long term, such as lipodystrophy (shrinkage or accumulation of body fat in certain parts). However, not all PLHIV will experience drug side effects, and in general, the side effects that arise can be managed well. Considering that the benefits of therapy are greater than the risks of morbidity and death that threaten PLHIV, ARV therapy still needs to be carried out [22, 23].

Saturation and boredom in taking ARV medication were experienced by PLHIV in this study. This happens because PLHIV have to take medication for the rest of their lives every day and must not miss it. PLHIV's boredom in taking ARVs is due to the necessity of taking the same drugs for life. Therefore, support is needed from family and the surrounding community so that PLHIV do not despair. PLHIV in this study also felt stigma, which caused them to feel uncomfortable taking ARV medication; for example, when socializing, they felt embarrassed about taking ARV medication in front of their friends. Based on research on urban teenagers, PLHIV who underwent anti-retroviral treatment procedures in the United States stated that 50% of the sufferers studied sometimes had to skip the obligation to take their medication because they were afraid that their friends or family would find out about their status as HIV sufferers. The status of being PLHIV affects social relationships and the emotional state of PLHIV, as the majority of respondents describe a low quality of life in social relationships, which is followed by the psychological state of the respondents. Increasing the abilities of PLHIV has a significant relationship with the quality of life in PLHIV. Enhancing the abilities of PLHIV cannot be separated from the support system provided to them, one of which is social support. Social support is comfort, attention, appreciation, or assistance in other forms that individuals receive from other people or groups. Strategies for improving the abilities of PLHIV include self-efficacy for PLHIV, empowerment, motivational interviews, and support groups [24]. One way is through peer group support with a chronic care model approach, namely nursing intervention focused on a support system that will impact the individual's belief in their ability to process, plan, and modify behavior to achieve a better quality of life.

People living with HIV who have little family support may have difficulty managing their emotions [25]. Currently, health and family support interventions may be associated with lower global quality of life scores in ARV adherence [26]. This study shows that the closer the couple, the better the ARV adherence. Therefore, family support is very important in maintaining an adaptive social response to PLHIV so that families can provide meaningful support for those affected. Partner intimacy also influences the level of adherence; most PLHIV (61.74%) reported high partner intimacy, around 93.91% of PLHIV used first-line ART, and 88.69% adhered to ART. Closeness to a partner is significantly associated with adherence to antiretroviral treatment [27]. Apart from family support, social support also improves the quality of life of PLHIV; routine family support and strong social support can positively influence routine health services and the completion of routine care for PLHIV sufferers.

5. Conclusion

The quality of life of PLHIV is shown to be related to the patient's level of ability and ART adherence. The better the patient's ability and adherence to ART, the quality of life of PLHIV will also show an improvement. Therefore, it is very

necessary to strengthen patients' abilities in daily life and ensure patient ART compliance so that their quality of life can improve.

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