Perception, Knowledge and Adherence to Antiretroviral Theraphy (ART) among Mother PLHIV in Yogyakarta

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ABSTRACT

Based on WHO 2019, there were 38 million people living with HIV (PLHIV), this figure has increased by 24% compared 2010. Globally more women were living with HIV in 2019 than men. In the same year, 85% of women and girls globally had acces to antiretroviral therapy (ART) to prevent mother-to-child transmission (MTCT). However, high ART coverage levels do not reflect the continued transmission that occurs after women are initially counted as receiving treatment. The purpose of this study was to know perception, knowledge and adherence ART. This research was quantitative research with crosssectional desaign. The research was conducted at the Victory Plus Foundation in 2020. The number of respondents in this study was mothers with HIV who had toddler as 39 respoden. Majority of respondents are 20-35 years old, senior high school education, housewives, married, last delivery by section cesarean and children with negative HIV. Majority of respondents have good knowledge, perception of HIV has positive and adherence to ARV theraphy.

Keywords: knowledge, perception, adherence ARV, mother PLHIV

INTRODUCTION

The first of 10 core commitments within the UN General Assembly's 2016 Political Declaration on Ending AIDS are the 90–90–90 targets, which aim to bring HIV testing and tnreatment to the vast majority of people living with HIV by 2020, and to reduce the amount of HIV in their bodies to undetectable levels that will keep them healthy and prevent further spread of the virus. Achieving the 90–90–90 target results in a minimum of 73% of people living with HIV having suppressed viral loads. Globally, there have been gains across the HIV testing and treatment cascade. At the end of 2019, 81% [68–95%] of people living with HIV knew their HIV status, and more than two thirds (67% [54–79%]) were on antiretroviral therapy, equal to an estimated 25.4 million [24.5 million–25.6 million] of the 38.0 million [31.6 million–44.5 million] people living with HIV—a number that has more than tripled since 2010.[1]

Based on WHO 2019, there are 38 million people living with HIV, this figure has increased by 24% compared 2010. Of the 3.8 million people living with HIV, 1.7 million are newly infected and 0.7 million HIV-related deaths. Globally more women were living with HIV in 2019 than men.[2] In the same year, 85% of women and girls globally had acces to antiretroviral therapy (ART) to prevent mother-to-child transmission (MTCT). However, high ART coverage levels do not reflect the continued transmission that occurs after women are initially counted as receiving treatment. Achieving retention in care and prevention of incident HIV infections in uninfected populations remain high priorities to reach global elimination targets. Since the global shift to, and accelerated rollout of, highly effective, simplified interventions based on lifelong ART for pregnant women living with HIV, virtual elimination of MTCT – also known as vertical transmission – has been shown to be feasible. [3]

Indonesia is one of the countries in the world reporting a rising number of new HIV infection in recent years, with a profile similar to countries with concentrated epidemics. [4] The number of HIV cases in Indonesia is fluctuate. However, in 2019 HIV cases peaked at 50,282 cases, while in 2018 there were 46,650. It means the highest case for eleven years since 2009. HIV and AIDS cases from 2017 to 2019 in Indonesia was mostly in Java. The percentage of reported HIV by sex, male was 64.5% while female was 35.5%. Women are a vulnerable group in HIV transmission. Women have a reproductive system can transmitting HIV to the fetus, women need special treatment in HIV prevention and transmission programs. Data on HIV sufferers by age group, the marginal age group of 25-49 years is at most 70.4%, then followed by the age group of 20-24 years where this age is a healthy reproductive age.[5]

The spread of HIV & AIDS has expanded to all provinces in Indonesia, one of which is the Special Region of Yogyakarta (DIY). HIV & AIDS cases in Yogyakarta are still found in infants less than 1 year old. This shows that the transmission of HIV & AIDS from mother to child still occurs in Yogyakarta. More than 90% of cases of children infected with HIV are transmitted through the process of mother to child transmission. The HIV virus can be transmitted from mother to child during pregnancy, during childbirth and while breastfeeding. Prevention Mother to Child HIV Transmission's Program (PMTCT) to be a very effective intervention to stop transmission virus from mother to child. In developed countries, the risk of children infected HIV from their mothers can be reduced to less than 2% due to the availability of PMTCT interventions with optimal services. In developing countries or poor countries, with minimal access to intervention, the risk of transmission still ranges between 20% and 50%.[6]

ART coverage by sex among adults 2019 secara global 73% women dan 61 % men sedangkan Asia Tengara 56% men, 65% women. Setiap tahun terjadi peningkatn ART coverage.(WHO). In nearly all regions, women living with HIV are more likely to access HIV testing and antiretroviral therapy than men, in part due to better healthseeking behaviour among women and the existence of HIV-related services designed specifically to reach women (such as services to prevent mother-to-child HIV transmission that are provided during antenatal care). In 2019, treatment coverage globally was 12 percentage points higher among women living with HIV than among men living with HIV, and viral suppression was 10 percentage points higher.[1]

Gains in treatment effectiveness, as well as increases in the number of people who know their status and are on treatment, are reflected in the fact that rates of viral load suppression among all people living with HIV rose by 44% (or 18 percentage points) between 2015 and 2019. Almost 59% [49–69%] of people living with HIV globally had suppressed viral loads in 2019. Increased access to antiretroviral therapy has averted an estimated 12.1 million AIDS-related deaths since 2010. The estimated 690 000 [500 000–970 000] lives lost due to AIDS-related illnesses worldwide in 2019 is a 39% reduction since 2010, but still far too many people dying unnecessarily.[1]

Alongside adolescent girls and young women, children living with HIV are often left without the support and services they need to stay healthy and build sustainable and enjoyable lives. The number of new child infections resulting from the mother-to-child transmission of HIV has more than halved in less than two decades, progress that in large part reflects the increased provision of antiretroviral therapy to pregnant women living with HIV. Despite this vastly improved treatment coverage, progress towards the elimination of child HIV infections has largely stalled, and the 2018 and 2020 targets for reducing new HIV infections among children were missed. Analyses of epidemiological and programme data are guiding efforts to address the remaining challenges, including treatment coverage gaps among pregnant women living with HIV, interruptions in antiretroviral therapy during pregnancy and breastfeeding, and women acquiring HIV during pregnancy and breastfeeding.[1]

HIV is treated with antiretroviral therapy consisting of one or more medicines. ART does not cure HIV but reduces its replication in the blood, thereby reducing the viral load to an undetectable level. ART enables people living with HIV to lead healthy, productive lives. It also works as an effective prevention, reducing the risk of onward transmission by 96%. ART should be taken every day throughout the person's life. People can continue with safe and effective ART if they adhere to their treatment. In cases when ART becomes ineffective due to reasons such as lost contact with health care providers and drug stockouts, people will need to switch to other medicines to protect their health.[7]

Antiretroviral drugs have great potential to prevent HIV transmission and acquisition, including through pre-exposure prophylaxis and post-exposure prophylaxis, by preventing mother-tochild transmission, and through antiretroviral therapy that achieves viral suppression.[8] Antiretrovirals are able to suppress the amount of HIV virus in the blood so that their immune system (CD4) is maintained. ARV theraphy must be taken regularly, on time and for life, to improve the quality of life of people living with HIV and prevent transmission. The Ministry of Health Republik Indonesia is accelerating ARVs with a target in 2020 as many as 258,340 PLWHA receive ARVs. In addition, social support from family and the closest environment is needed so that PLWHA stay enthusiastic and do not stop drugs[5]

Standard antiretroviral therapy (ARV) consists of the combination of antiretroviral (ARV) theraphy to maximally suppress the HIV virus and stop the progression of HIV disease. ARV also prevents onward transmission of HIV. Huge reductions have been seen in rates of death and infections when use is made of a potent ARV regimen, particularly in early stages of the disease. WHO recommends ARV for all people with HIV as soon as possible after diagnosis without any restrictions of CD4 counts. It also recommends offer of pre-exposure prophylaxis to people at substantial risk of HIV infection as an additional prevention choice as part of comprehensive prevention. Countries are now following to adapt and implement these recommendations within own epidemiological settings.[7]

Victory Plus is the Foundation that works too assist people with HIV & AIDS in Yogyakarta. Not all housewives with HIV positive routinely consume ARV. According to Precede-Procede theory, behavior is influenced by predisposing, resinforcing and enabling factors. In this research, predisposing factors like knowledge and perception as a variable in this study.[9] The aims of this study is to know the adherence mother with HIV who have toddlers to antiretroviral therapy.

MATERIAL AND METHOD

This study was conducted at the Victory Plus Foundation, it was engaged in providing direct assistance to people affected by HIV & AIDS in Yogyakarta, Indonesia. This research was a cross sectional study. The independent variables were knowledge and perception. The dependent variable was adherence antiretroviral theraphy. Respondent of this study were 39 mother with HIV who have toddler in Victory Plus to control antiretroviral theraphy. The inclusion criteria of this study were used antiretroviral therapy, have toddler, and agree to be respondent. The instrument of this study use questionnaire that has been tested for validity and reliability. Data collecting on 2020 and the ethical committee of health Poltekkes Kemenkes Yogyakarta number e-KEPK/POLKESYO/0578/IX/2020 granted the ethical approval for this study.

RESULTS AND DISCUSSION

Respondents in this study amounted to 39 mother diagnosed HIV and have a toddler. Respondent get ART and under monitoring from Victory Plus Foundation.

Socio-demographic characteristics

Characteristic responden of this study presented in the following table:

Tabel 1. Socio-characteristic of Respondents

Characteristic of Respondents	Total	Percentage (%)
Age		
20-35 years	27	69,2
>35 years	12	30,8
Education		
Not school	1	2.6
Elementery school	9	23.1
Senior high school	25	64.1
University	4	10.2
Occupational		
Housewife	28	71.,8
Employee	9	23,1
Others	2	5.1
Marital Status		
Married	30	79.5
Divorced	2	5.1
Death divorce	6	15.4
Type of delivery		
Normal delivery	18	46.2
Sectio Cesarea	21	53.8
Child HIV status		
Positive	10	25.6
Negative	20	51.3
Not evaluated	9	23.1

Based on the characteristics of the respondents, the majority of respondents are 20-35 years old, have high school education, housewives, married, last delivery by cesarean section, and children's HIV is negative. The age of 20-35 years is included in the healthy reproductive age, where a woman is less at risk of getting pregnant and this is the most sufferers ini HIV cases. The respondent of this research were PLHIV, mother who have a toddler and majority are married, last delivery by cesarean section and 25,6% their child are HIV possitive. Women's risk for HIV and identify intervenerable moments for HIV prevention.[10] Prevention of mother-to-child transmission (PMTCT) remains a cornerstone of HIV prevention and control efforts.[11] The rate of transmission of HIV from a mother to her child during pregnancy, labour, delivery or breastfeeding ranges from 15% to 45%. As such, identification of HIV infection should be immediately followed by an offer of linkage to lifelong treatment and care. [3] Prevention modalities include use of antiretroviral (ARV) regimens during pregnancy, labor and delivery, and postnatally to the infant; and elective cesarean delivery before amniotic membrane rupture in cases where the HIV load is still detectable in late pregnancy.[12] Sectio cesarean delivery in PLHIV has a high risk of transmission low (2-4%) or can reduce risk transmission up to 50-66%. [13]

Perception about HIV

Respondent's perception about HIV were present in the table:

Table 2. Perception about HIV

Variable	Total	Percentage (%)
Perception about HIV		
Negative	8	20.5
Positive	31	79.5

Majority of respondent have a positive perception about HIV (79,5), but 20,5% respondent have negative perception about HIV. Perception about HIV are divided itu several topics in the following table:

Table 3. Topic of Perception

Topic	Total	Percentage (%)
Lost colleggues		
Yes	7	18
No	32	82
Offended by people reaction		
Yes	6	15,4
No	33	84,6
Avoid touching if know PLHIV		
Yes	4	10,3
No	35	89,7
Stopp socializing because of they react to you		
Yes	3	7,7
No	36	92,3
Family stop calling you		
Yes	0	0
No	39	100
People afraid with you		
Yes	1	2,6
No	38	97,4
Physically avoid you		
Yes	2	5,1
No	37	94,9
Physically distancing with you		
Yes	5	12,8
No	34	87,2
Afraid of their children near you		
Yes	1	2,6
No	38	97,4
Forgot your goodness after know PLHIV		
Yes	4	10,3
No	35	89,7
Regret telling them about your HIV status		
Yes	5	12,8
No	34	87,2

Based on the table 3, the respondent feels that no family has stopped calling after after they know HIV status. This shows that people are still in contact with the telephone even though they know HIV status. The lowest percentage of respondent's perception that they will lost collegues because they know she is PLHIV.

Risk perception for HIV infection is an important determinant for engaging in HIV prevention behaviour.[14] Adherence to ART is a continuous process influenced by the dynamics of perceptions among PLHIV related to their HIV diagnosis, ART and the quality of HIV-related care they had received from healthcare facilities[15]. All of the respondent are sure that their families are still call them, but 18% respondent stated that they lost collegues after knowing that they were PLHIV. In this study, PLHIV felt that it was acceptable to the community.

Knowledge about HIV

Table 4 present the level of knowledge mother among PLHIV about HIV and transmitting of HIV.

Table 4. Level of Knowledge about HIV

Level of Knowledge	Total	Percentage (%)
Poor	14	35,9
Good	25	64,1

Majority of respondent have good knowledge about HIV (84,6%). To further clarify the knowledge of respondents was presented in the following table:

Tabel 5. Topic of Knowledge about HIV

	True		False	
	n	%	n	%
HIV				
HIV is an infection disease that attacks the human immune system	35	89,7	4	10,3
HIV positive means she had AIDS	33	84,6	6	15,4
HIV is no symptom	32	82	7	18
HIV is found in blood, urine, sweat and semen	19	48,7	20	51,3
Prevention HIV				
Use condom	36	92,3	3	7,7
Transmission of HIV				
Swimming	39	100	0	0
Sharing eating utensils	39	100	0	0
Mosquito bites	38	97,4	1	2,6
Coughin or sneezing	37	94,9	2	5,1
Pregnant mother to baby	32	82	7	18
Neddles	36	92,3	3	7,7

Based on the table 5, all of the respondents answered correctly on the statement of HIV is not transmitted when swimming and sharing eating utensils. 18% of mother do not know that HIV can be transmitted from mother to baby during pregnancy and mojority have a less knowledge about HIV found in blood, urine, sweat and cemen. As for the level of knowledge, the majority have good knowledge about HIV. Ukaegbu research states that women's age, educational level were consistenly associated with knowledge about HIV. [16] In this research, majority respondent have a good education (senior high school) allow for influencing a good knowledge. Majority respondent (51,3%) didn't know about HIV is found in blood, urine, sweat and semen. This point is a note for provider to give education about the HIV virus so that PLHIV know and can prevent HIV transmission.

Adherence ART

Aherence ART is taking ARV on schedule and never misiing them. The following table presents the crosstab between independent variable and adherence ART

Tabel 6. Croostabulation Adherence ART

Variable	Adherence ART					
	Yes		No		Total	
	n	%	n	%	n	%
Age						
20-35 years	17	63	10	27	27	100
>35 years	8	66,7	4	33,3	12	100
Education						
Not school	0	0	1	100	1	100
Elementery school	3	33,3	6	66,7	9	100
Senior high school	19	76	6	24	25	100
University	3	75	1	25	4	100
Occupational						
Housewife	19	67,9	9	32,1	28	100
Employee	5	55,5	4	44,5	9	100
Others	1	50	1	50	2	100
Marital Status						
Married	22	71	9	29	31	100
Divorced	0	0	2	100	2	100
Death divorce	3	50	3	50	6	100
Type of delivery						
Normal delivery	11	61,1	7	38,9	18	100
Sectio Cesarea	14	66,7	7	33,7	21	100
Child HIV status						
Positive	8	80	2	20	10	100
Negative	11	55	9	45	20	100
Not evaluated	6	66,7	3	33,3	9	100
Perception about HIV						
Negative	4	50	4	50	8	100
Positive	21	67,7	10	32,3	31	100
Level of Knowledge						
Poor	11	78,6	3	21,4	14	100
Good	14	56	11	44	25	100

Majority of respondent who have adherence ART are from the age group >35 years (66,7%), senior high school and university, housewife (67,9%), married (71%), section cesarean in delivery (66,7), children with HIV (80%), habe positive perception and poor knowledge about HIV (78,6%). This study also presents how respondents carry out ARV Therapy

Table 7. Distribution of ART

Topic	Total	Percentage (%)
ART with recommendation doctor		
Yes	38	97,4
No	1	2,6
ART even tough get side effect		
Yes	38	97,4
No	1	2,6
Take ARV at the same time		
Yes	34	87,2
No	5	12,8
Always carry ARV		
Yes	33	84,6
No	6	15,4
Have stock ARV		
Yes	30	76,9
No	9	23,1
Have reminder to ARV		
Yes	30	76,9
No	9	23,1

Based on the table, it was obtained that the highest correct answer was in the question of how to take ARVs according to the doctor's instructions and continue to take ARVs even though side effects appeared. Respondents have adherence with doctor's advice. As for the lowest correct answer is respondent do not reminder to ART and not having stock of ARV theraphy.

ART adherence among women are an effort to prevent HIV transmission. 64,1% respondent were adherence to ART. Respondent who adherence to ART were majority >35 years old, at the age above the healthy reproductive age maturity to think and tend to follow the rules. Besides that the ART adherence among women were have children with possitive HIV. Research by Tri Hastuti that family support has a significant relationship with maternal adherence totaking ARVs with an OR of 27.5 (95%).[17], have possitive perception but have loss knowledge about HIV.

According to the Precede Proced theory, behavior is influenced by predisposing, reinforcing and enabling factors. Knowledge and perception are include in predisposing factors and the behavior is ART adherence.[9]

Several literatures explain the factors that lead to ART adherence including Laws research which stated that most knowledge domains were not significantly associated with self-reported ARV adherence.[18] In this study, respondents' adherence to ARV was caused by other factors besides perception and knowledge. Research by Latif et al showed that knowledge about antiretroviral treatment and perception of knowledge had a relationship with adherence to taking ARVs, but the most influential factor on adherence to taking ARVs was a history of drug side effects (never experienced drug side effects).[19] Others factors that may affect adherence to taking ARVs include The result of Andini et all showed that adherence to taking ARVs was related to the level of self-confidence.[20] Adherence to ARV theraphy are influenced by internal and external factors.

The majority of respondents have adherence in ARV theraphy. Research by Adeniyi et al., stated that based on the results of qualitative data analysis, it was revealed that lifestyle, side effects of ARVs, being away from home and the presence of stigma at work made mothers not comply with taking ARVs.[21] When compared with this study, adherence was low at the point that mothers often forgot,

did not have a special alarm to remind them to take ARVs and did not have stock of ARV theraphy. Non-adherence to taking ARVs is almost a record for people with HIV. This finding aligns with that study of a 2019 studi by Nurfalah etc found that there are more women with HIV in Lampung, who do not adhere to their ARV therapy than women who do.[22] Non-adherence to ARV therapy can be caused by several factors, including therapy-induced side effects, excessive medication, or saturation. Women with HIV and AIDS must deal with these illnesses throughout their lives, so they must consistently follow ARV therapy to maintain a good quality of life.[23] A lack of familial support, critical peers, and socioeconomic conditions can also make women with HIV not to adhere to their ARV therapy.[24]

Adherence can be influenced by internal and external factors. The internal supporting factors of adherence to ARV were the motivation to live longer, the eagerness to get cured and to be healthy, considering ARV as vitamin, and the faith in their own religion. Besides, the availability of ARV and social supports were other supporting factors. The social supports were support from family, responsibility and affection for their children, willingness to get married, support from peer groups, NGO staffs, and religion figures, and good relationship with health provider staffs. The internal factors should be improved by motivating PLHIVs while external factors should include family, peer groups, NGO staff and health provider, provide better accessibility and affordability to ARV, and educate the society.[25]

Recommendations from Suryaningdyah's research as an effort to improve adherence in ARV theraphy by increasing motivation to take ARV continuous, increasing supporting family, improving the ARV health care system, increasing service satisfaction trough excellent service quality, increasing ARV treatment adherence, trough regular monitoring.[26]. Poor adherence remains a major barrier to achieving the clinical and public health benefits of antiretroviral theraphy (ARVs). A systematic review and qualitative meta-synthesis was conduct to evaluate how ARV adverse drug reactions may influence ARV adherence. Thirty-nine articles were identified, and 33 reported that ARV adverse drug reactions decreased adherence and six studies found no influence. Visually noticeable adverse drug reactions and psychological adverse reactions were reported as more likely to cause non-adherence compared to other adverse drug reactions. Six studies reported a range of adverse reactions associated with EFV-containing regimens contributing to decreased adherence. Informing HIV-infected individuals about ARV adverse drug reactions prior to initiation, counselling about coping mechanisms, and experiencing the effectiveness of ARVs on wellbeing may improve ARV adherence.[27] Study from Mbengue in Senegal findings imply that adherence should be routinely assessed during medical visits. Ongoing strategies to improve adherence such as out-of-clinic group-based models or psychological support should be directed toward outpatients' clinics to assist in improving adherence and long term virologic suppression in Senegal.[28]

CONCLUSION

Majority of respondents are 20-35 years old, senior high school education, housewives, married, last delivery by section cesarean and children with negative HIV. Majority of respondents have good knowledge, perception of HIV has positive and adherence to ARV theraphy.

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