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# Analysis of Informational Support and Appreciation for People Living with People with HIV/AIDS as a Result of Lost Follow Up of HIV/AIDS Patients in West Muna Regency

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ABSTRACT

**Introduction:** Comprehensive services are needed to resolve the complex problem of PLWHA infection. One of the comprehensive services can be implemented with the help of people or family members who live with PLWHA and provide attention to them. Efforts that need to be made to slow down the incidence of opportunistic infections in HIV clients include reducing the incidence of lost to follow up. Until now, there has been no data related to the relationship between PLWHA (People Living with PLWHA) and the incidence of lost to follow up in HIV patients in West Muna Regency.

**Method:** Quantitative research using Case Control Study design, Population is all HIV/AIDS patients registered in the Disease Control Division of West Muna Regency as many as 38 people. Case samples are 11 people and Control Samples are 11 people.

**Result:**Instrumental support is significantly related to the incidence of Lost to Follow Up in HIV/AIDS patients with a p value = 0.008 (<0.05) and informational support is significantly related to the incidence of Lost to Follow Up in HIV/AIDS patients with a p value = 0.03 (<0.05).

**Conclusion:** The absence of instrumental and informational support from OHIDHA will increase the risk of Lost to Follow Up for HIV/AIDS patients, whereas HIV/AIDS patients who receive instrumental and informational support from OHIDHA will reduce the incidence of Lost to Follow Up.

## Introduction

AIDS is a collection of symptoms of disease that appear due to the presence of the human immunodeficiency virus (HIV).[1] This virus is found in bodily fluids, especially vaginal fluids, semen, blood and breast milk.[2] Viruses affect the human immune system and cause the body's defenses to be weakened or absent, which can

easily lead to infectious diseases.[3] HIV is a virus that attacks a person's immune system, weakening a person's ability to ward off incoming diseases. When the immune system is weakened, it can cause health problems. Common symptoms are persistent diarrhea, coughing and fever.[4] A collection of symptoms of disease caused by the weakening of the immune system by HIV is called AIDS.[5]

HIV infection is a health problem that needs attention because more and more people are living with HIV/AIDS (PLWHA). Data from the United Program on HIV and AIDS (UNAIDS) shows that the number of PLWHA infections worldwide in 2016 was 36.7 million PLWHA.[6] That number is up from 34.6 million people living with HIV since 2015.[7] HIV and AIDS are major health problems in human life, based on data in 2017, around 36.9 million people were infected with HIV, including 1.8 million new cases, and around 940 deaths in the world were caused by HIV and AIDS.[8]

HIV/AIDS is a disease that is increasing and is a global problem that has affected the world and also Indonesia.[9] This infection was discovered in the late 20th century, in 2011 more than 60 million adults and children were infected with HIV and almost 20 million people had AIDS. There were a total of 36.7 million HIV/AIDS patients worldwide. Global detection of HIV cases decreased by 6 percent. In 2010 the number of people infected with HIV was 2.2 million, in 2015 it fell to 2.1 million. AIDS-related deaths in 2005 were 2 million people, down 45% in 2015 to 1.1 million deaths from AIDS.[10]

According to the data from Ministry of Health of the Republic of Indonesia, In March 2021, the number of people living with HIV (HIV cases) reported was 427,201, while the number of AIDS cases reported in March 2021 was 131,417. The estimated number of PLWHA in 2020 was 543,100 people. The number of PLWHA found (419,551) and reported reached 77% of the estimated number of living PLWHA (543,100). PLWHA who routinely receive ARV treatment are 26% (142,906) of the estimated PLWHA (543,100) with lost to follow up/LFU after starting ARV treatment (65,779) of 26% of PLWHA who have started ARV treatment (262,693).[11]

Based on data Health Office of Southeast Sulawesi, since 2015 to 2022, there were 1257 HIV sufferers and 894 AIDS cases. The 3 regencies/cities with the highest HIV/AIDS populations are Kendari City (HIV 420, AIDS 234), Bau-bau City (HIV 94, AIDS 232) and South Konawe Regency (HIV 113, AIDS 72). West Muna Regency itself only had 16 HIV cases and 16 AIDS cases, but with the percentage of lost to follow up reaching more than 70%.[12]

Current HIV/AIDS treatment is that patients are given antiretroviral therapy (ARV) as soon as possible after being diagnosed with HIV. To get ARV therapy, PLWHA should come to health services to take medication. The absence of patients to the VCT clinic to take ARV for control for more than 90 consecutive days is called Lost To Follow Up (Handayani et al., 2017). The Indonesian Ministry of Health reported in December 2013 that 12,779 patients (17.32%) with HIV/AIDS were lost to follow up.[13]

In West Muna Regency itself, the number of HIV positive cases has not increased in the last 3 years, which is 38 people. However, the incidence of Lost to follow-up has increased every year in the last 3 years, based on data from the West Muna Regency Health Office in 2019 there were 6 (six) patients Lost to follow-up, then in 2020 there were 7 (seven) patients Lost to follow-up, and finally in 2021 there were 6 (six) patients Lost to follow-up, while in 2022, based on data until July 2022 there have been an additional 3 (three) HIV positive patients who were Lost to follow-up.

PLHIV who are lost to follow up have an impact on both clinical and ARV therapy.[14] At the clinical level, the continuation of ARV treatment in patients with HIV who do not follow up (Lost to Follow Up) cannot be assessed. People living with HIV who decide to stop treatment have a higher risk of death. This is because the immune system that was previously controlled by the use of ARV drugs becomes weakened and allows PLWHA to become weak against opportunistic infections that lead to death of the sufferer.[15]

OHIDHA support is a form of interpersonal relationship in the form of actions and attitudes of family acceptance of sick family members.[16] The existence of OHIDHA support can result in emotional benefits or influence the behavior of sufferers. However, the opposite condition occurs if OHIDHA support is felt to be lacking, especially for PLWHA, because PLWHA actually need support without stigma and discrimination. In this situation, PLWHA who do not feel they have

social support, feel emotionally lacking due to low attention from people around them, do not get impressions or suggestions that can increase their motivation in life.[17] As a result, PLWHA will experience changes in the behavior of accepting people around them. This affects the reluctance of PLWHA to continue the treatment process, thus potentially causing the ARV treatment process to be hampered so that the incidence of lost to follow up increases.

In the researcher's initial observation, HIV/AIDS patients who still come to the clinic to get their medicine are often accompanied by OHIDHA, this incident is included in the reinforcing factor, in this case informational support. Furthermore, the researcher had time to ask the accompanying OHIDHA, regarding the reason for their willingness to accompany PLWHA because the informant felt that the problems faced by PLWHA were also felt by them, and assumed that, as relatives, these problems should be faced together, this is included in the category of emotional support. Several PLWHA who no longer visit the clinic, reasoned that the location of their residence was far from the health service and there were no relatives who wanted to accompany them, based on this the researcher assumed that the absence of instrumental support from OHIDHA could cause PLWHA to be lost to follow up. In addition, support for appreciation was also not felt by PLWHA, because in undergoing their treatment, PLWHA felt shunned by those closest to them.

Lost to follow up by HIV/AIDS patients results in discontinuation of treatment and increased risk of death.[15] The effects of the loss of follow-up care for patients with HIV/AIDS include more frequent treatment interruptions and fewer deaths in urban areas than in rural areas.[18] For prevention, there must be identification and analysis of dominant factors that influence lost to follow up of HIV patients. Until now, there has been no data related to the relationship between OHIDHA (People Living with PLWHA) and the incidence of lost to follow up in HIV patients in West Muna Regency. Therefore, researchers are interested in raising this theme as a study entitled "Analysis of Informational Support and Appreciation for People Living with People with HIV/AIDS as a Result of Lost Follow Up of HIV/AIDS Patients in West Muna Regency".

## Method

Quantitative research using Case Control Study design, Population is all HIV/AIDS patients registered in the Disease Control Division of West Muna Regency as many as 38 people. The case population is HIV/AIDS patients who have not visited the VCT clinic within 180 days (3 months), which is 27 people. The control population is HIV/AIDS patients who still visit the VCT clinic within 180 days (3 months), which is 11 people.

Since the type of case raised is a disease that is still rarely found in the community, a 1:1 comparison is used in the number of case and control samples in this study. The case sample is HIV/AIDS patients who have not visited the VCT clinic within 180 days (3 months), which is 11 people. The control sample is HIV/AIDS patients who still visit the VCT clinic within 180 days (3 months), which is 11 people.

## Results

**Table 1** shows that the proportion of instrumental support from OHIDHA for HIV/AIDS patients is higher in the control group, which is 90.9% compared to the case group, which is 27.3%. Informational support is higher in the control group, which is 81.8% compared to the case group, which is only 27.3%. The same thing is also seen in emotional support, in the control group it looks higher, which is 90.9% compared to 36.4% in the case group. Likewise, the case group's appreciation support is higher by 90.9% compared to the control group, which is only 36.4%.

**Table 2** shows that the risk of instrumental support that the results of the statistical test obtained a p value = 0.008 (<0.05) which means that instrumental support is significantly related to the incidence of Lost to Follow Up in HIV/AIDS patients. The results of statistical analysis with the chi square test obtained an OR value of 26.667 at a confidence level (CI) = 95% with a lower limit = 2.309 and an upper limit = 308.00 Because the OR value> 1, OHIDHA instrumental support is a risk factor for the incidence of Lost to Follow Up in

HIV/AIDS patients. The absence of OHIDHA instrumental support will increase the risk of Lost to Follow Up in HIV/AIDS patients by 26.667 times greater than HIV/AIDS patients who receive instrumental support from OHIDHA. Because the lower limit and upper limit values do not include the value 1, the value of 26.667 is considered significant.

Based on the risk factors of informational support, it can be seen that the results of the statistical test obtained a p value = 0.03 (<0.05) which means that informational support is significantly related to the incidence of Lost to Follow Up in HIV/AIDS patients. The results of statistical analysis with the chi square test obtained an OR value of 12.00 at a confidence level(CI) = 95% with a lower limit = 1.581 and an upper limit = 91.084. Because the OR value> 1, OHIDHA informational support is a risk factor for the incidence of Lost to Follow Up in HIV/AIDS patients. The absence of OHIDHA informational support will increase the risk of Lost to Follow Up in HIV/AIDS patients by 12 times greater than HIV/AIDS patients who receive informational support from OHIDHA. Because the lower limit and upper limit values do not include the value 1, the value of 26.667 is considered significant.

**Table 1.**
**Distribution of Proportion of Risk Factors for Lost to Follow Up Incidents in HIV/AIDS Patients in West Muna Regency**

| Exposure Factors | *Lost to Follow Up* | | | |
|---|---|---|---|---|
| | Case | | Control | |
| | n | % | n | % |
| Instrumental Support | | | | |
| - Enough | 3 | 27.3 | 10 | 90.9 |
| - Not enough | 8 | 72.7 | 1 | 9.1 |
| Informational Support | | | | |
| - Enough | 3 | 27.3 | 9 | 81.8 |
| - Not enough | 8 | 72.7 | 2 | 18.2 |
| Emotional Support | | | | |
| - Enough | 4 | 36.4 | 10 | 90.9 |
| - Not enough | 7 | 63.6 | 1 | 9.1 |
| Support Awards | | | | |
| - Enough | 4 | 36.4 | 10 | 90.9 |
| - Not enough | 7 | 63.6 | 1 | 9.1 |

**Table 2.**
**Risk Factors Influencing Lost to Follow Up in HIV/AIDS Patients in West Muna Regency**

| Exposure Factors | *p-value* | OR | CI 95% |
|---|---|---|---|
| Instrumental Support | 0.008 | 26,667 | 2,309 – 308,000 |
| Informational Support | 0.030 | 12.00 | 1,581 – 91,084 |

## Discussion

### Instrumental Support

The results of the study indicate that instrumental support is a risk factor for the occurrence of Lost to Follow Up in HIV/AIDS patients, which means that the absence of instrumental support from OHIDHA increases the possibility of Lost to Follow Up in HIV/AIDS

patients. Family instrumental support is a financial function and health care function applied by OHIDHA to sick people living with HIV. This support can be in the form of providing materials that can provide direct assistance such as providing money, goods, energy, or services. This form can reduce stress because individuals can have a direct impact on solving problems related to material.

This research is in line with research of Berkanis who examined the influence of family support on the self-esteem of TB patients in Kupang City, which stated that there was an influence of instrumental support on the self-esteem of TB patients. Self-esteem is obtained from oneself and others, namely being loved, respected and appreciated. Individuals will feel high self-esteem if they often experience success, conversely individuals will feel low self-esteem if they often experience failure, are not loved or are not accepted by their environment. The higher the self-esteem of a patient, the stronger their desire to be healthy so that they are willing to continue treatment.[19]

The lack of instrumental support for people with HIV/AIDS can have a significant impact on their desire to undergo treatment. Instrumental support includes concrete assistance, such as access to medical care, medication, transportation to a health facility, or other practical aspects that support adherence to HIV/AIDS treatment. Basic needs such as food, safe housing, or access to clean water become difficult to meet for people with HIV/AIDS who may be experiencing financial hardship. When these basic needs are not met, they may prioritize finding food over undergoing treatment.

HIV/AIDS treatment is often complex and requires high discipline in taking medication regularly and on time. Without adequate instrumental support, people with HIV/AIDS may have difficulty taking this treatment consistently. This can result in decreased effectiveness of treatment and increased risk of drug resistance.

Lack of instrumental support can also cause stress, depression, and anxiety in people with HIV/AIDS. This can affect their mental well-being, which in turn can affect their willingness to undergo treatment. Thus, it is important for people with HIV/AIDS to have adequate access to instrumental support such as access to medicines, medical care, financial assistance, and social support. These factors play a significant role in increasing their willingness and ability to undergo effective HIV/AIDS treatment, improving their quality of life, and reducing the risk of transmission to others.

**Informational Support**

The results of the study showed that informational support is a risk factor for the occurrence of Lost to Follow Up in HIV/AIDS patients, which means that the absence of informational support from OHIDHA increases the possibility of Lost to Follow Up in HIV/AIDS patients. Informational support includes providing relevant and important information to patients to help them understand their condition, decide on appropriate treatment, and understand the importance of consistency in following treatment.

The results of this study are not in line with research from Husna which examines the analysis of social support with adherence to antiretroviral (ARV) therapy in HIV/AIDS patients in Banda Aceh, with statistical test results of p = 0.374 which concludes that there is no significant relationship between informational support and adherence to ARV therapy in HIV/AIDS patients.[20] However, in another study by Tahir et al. (2020) with statistical test results showing p = 0.048 which means that there is a relationship between informational support and ARV adherence in HIV/AIDS patients in Makassar City.

Informational support is an integral part of HIV/AIDS patient care. It includes providing accurate and understandable information about the virus, treatments, medication side effects, and the importance of adherence to treatment. Informational support also involves education about safe sex practices, counseling about stigma and discrimination, and assistance in accessing needed health resources and services.

Informational support helps HIV/AIDS patients to better understand their condition. Patients who have a good understanding of their disease are more likely to follow their treatment diligently because they are aware of its positive impact on their health. HIV/AIDS patients often face social stigma and fear. Informational support helps them overcome these fears by providing correct information and dispelling false myths

about HIV/AIDS. Patients who are more confident are more likely to stick to their treatment.

Informational support can help patients make informed decisions about their care. Patients who have a good knowledge of their care are more likely to follow medical guidelines correctly, which in turn can improve the effectiveness of their care. Informational support also includes counseling and emotional support. This is important because HIV/AIDS patients often face significant emotional stress. This support can help them cope with stress and depression that may arise during their care.

Informational support plays a very important role in influencing the incidence of lost to follow-up in HIV/AIDS patients. Providing appropriate information, education, counseling, and emotional support can help patients overcome various obstacles that may arise during their care. With increased understanding, confidence, and quality of care, HIV/AIDS patients are more likely to adhere to their care, which will ultimately improve their quality of life and reduce the spread of HIV/AIDS. Therefore, it is important for health care systems to prioritize informational support as an integral part of HIV/AIDS care.

## Conclusion

The absence of instrumental and informational support from OHIDHA will increase the risk of Lost to Follow Up for HIV/AIDS patients, whereas HIV/AIDS patients who receive instrumental and informational support from OHIDHA will reduce the incidence of Lost to Follow Up.

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