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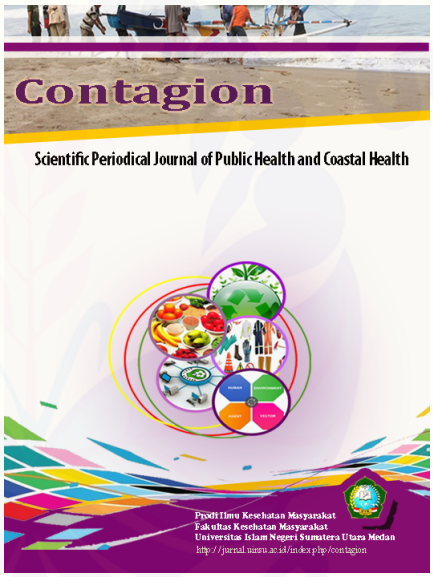

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Exploring Peer Support as a Strategy to Reduce Stigma among PLHIV in Jember Regency

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Abstract

***Background**: Efforts to reduce stigma and discrimination are important factors in efforts to reduce HIV cases, especially mortality, and increase the treatment rate for PLHIV.*
*Objective: This study aimed to obtain evidence of efforts to reduce stigma and discrimination in healthcare facilities **Methods**: This research is a Mix Methods study. The population was HIV/AIDS patients in the Puger and Kencong areas. The sampling technique was purposive sampling. The variables included the level of discrimination, medication adherence, and stigma reduction strategies. Quantitative data were analyzed descriptively, and qualitative data were analyzed by content analysis. **Results**: the level of discrimination felt by PLHIV is 100% which is low. While the level of adherence to taking medication for the majority of PLHIV is classified as high, namely 69.7%. The success in reducing stigma and discrimination in health services is influenced by factors that accompany PLHIV and health workers, where assistants always help PLHIV in carrying out examinations, and officers are also friendly to PLHIV, so this is what can make discrimination experienced by PLHIV low. **Conclusion**: Success in reducing stigma and discrimination in healthcare facilities was proven by high adherence to taking medication, and the low level of discrimination experienced by PLHIV.*

Keywords: *PLHIV, HIV/AIDS, discrimination, stigma, strategy*

INTRODUCTION

HIV/AIDS cases globally are estimated at 38.4 million cases with an estimated 0.7% of sufferers aged 15-49 years. Meanwhile, there will be 650,000 cases of death due to HIV and co-morbidities by 2021 (WHO, 2022). HIV/AIDS cases in Indonesia tend to increase. It is known that over the past eleven years, the number of HIV/AIDS cases has increased with the peak of the highest cases being in 2019 with 50,282 cases. Meanwhile, the province with the highest cases of HIV/AIDS in East Java Province with a total of 8,935 infections (Kemenkes RI, 2020). Based on data compiled by the Jember District Health Office, the number of HIV/AIDS cases in 2020 was 595 cases and increased in 2021 to 637 cases. Thus, making Jember Regency one of the districts with a high rate of HIV/AIDS cases in East Java Province.

Cases of HIV/AIDS in Indonesia are increasing every year, the majority occur in men with a percentage of 68.60% in the productive age category with the main risk factors still being in the heterosexual group of 70% and followed by the homosexual group of 22 %. The high number of cases of HIV/AIDS in Indonesia, apart from being able to overcome it by providing counseling to prevent

HIV transmission, can be done by carrying out routine antiretroviral (ARV) treatment efforts for those who are HIV/AIDS positive. According to data from the Ministry of Health as of 2020, there were 142,906 PLHIV who were receiving treatment, while as many as 65,779 PLHIV dropped out of medication or lost to follow-up (LFU), and 6,354 PLHIV stopped treatment (Kementrian Kesehatan RI, 2021). Giving of stigma PLHIV is one of the factors why PLHIV have emerged who choose to stop treatment. As many as 82.1% of female PLHIV and 88.3% of male PLHIV experienced discriminatory behavior from their surroundings. With 40-50% of discrimination coming from their community and 67-68% experiencing discrimination from family members and people around them (BKKBN et al., 2018). In addition to discrimination and stigma from the community and family, PLHIV may experience discrimination from healthcare workers. This is supported by similar research which states that PLHIV is discriminated against and refused services at healthcare facilities (Lestari & Villasari, 2021). Other research also proves that PLHIV tends to get different services while in health care facilities (Kay et al., 2018). The emergence of shame and fear of discrimination can influence PLHIV to carry out routine checks and take ARV drugs at designated health services.

Based on the preliminary study of PLHIV and PLHIV peer support, currently, PLHIV patients feel that discrimination in health services has decreased, while the stigma that still exists is the perspective of medical personnel towards PLHIV. In addition, forms of direct discrimination such as giving criticism and expressing sentences that can make PLHIV feel uncomfortable are often found by PLHIV when they are in healthcare settings, especially in hospitals. Stigma and discrimination against PLHIV in health services are related to the level of knowledge and perspective of health workers (Mahamboro et al., 2020). The lack of training on how to handle HIV/AIDS patients, the low knowledge of officers regarding the transmission of HIV/AIDS transmission, and the fear of infection are the reasons why discrimination against PLHIV is still found in the health services (Fauk et al., 2021). Most health workers and paramedics who commit discriminatory acts are staff outside the scope of HIV/AIDS services, for example in administrative departments, drug collection, and parking lots.

However, in addition to discrimination and stigma from the environment and health workers, based on preliminary studies it was found that there is a stigma that arises from within the PLHIV themselves (self-stigma). This self-stigma can be in the form of the fear of PLHIV undergoing treatment and meeting with health workers because of the emergence of fear of not being accepted and not confident, so this can also result in PLHIV choosing not to seek treatment or dropping out of medication or avoiding HIV/AIDS counseling activities. Research related to incidents of discrimination among PLHIV continues to be carried out to prevent and reduce cases of discrimination in health services as well as the perception of self-stigma among PLHIV. Handling and preventing discrimination and stigma can play an important role in the willingness of PLHIV to

continue undergoing treatment and counseling. Handling stigma and discrimination can be an important factor in efforts to reduce cases, especially cases of HIV mortality, and increase the treatment rate for PLHIV. So based on the description above, this study aimed to identify efforts to reduce stigma and discrimination in healthcare facilities in the Jember Regency area.

METHODS

The research used a Mixed Methods Design with an embedded approach. Mixed Methods Design with an embedded approach is an interpretation of two approaches, qualitative and quantitative. Quantitative methods aim to explain the differences between the variables studied and qualitative methods aim to explore and explain more deeply the phenomena found in research. This research was conducted in the concentration of prostitution in the Puger and Kencong subdistricts, Jember Regency in September 2022. The population in the study was 33 HIV/AIDS patients who were in the Puger and Kencong localization areas. The sampling technique in this study was carried out by purposive sampling. Variables examined in this study include the level of discrimination and adherence to taking medication for a quantitative study, and for a qualitative study, strategies for reducing stigma and discrimination from caregivers of PLHIV. In this study, the respondents to the quantitative study were HIV patients, while the informants in the qualitative study who were interviewed were divided into 3 namely main informants, key informants, and additional informants. The main informants consisted of HIV patients, PLHIV peer support, and health workers. The key informants were the management of the Laskar NGO and additional informants, namely PLHIV. The research instruments used to measure medication adherence were the Standardized Brief Questionnaire and the Morisky Medication Adherence Scales-8 (MMAS-8). The researchers cross-checked the results with the PLHIV peer support. Quantitative data were analyzed descriptively, and qualitative data were analyzed by content analysis. Data is presented using tables, narration, and quotations.

RESULTS AND DISCUSSION

Discrimination of Health Officers in Healthcare

The level of discrimination from the health officers in healthcare received by PLHIV in Jember Regency was all the respondents stated that 33 people (100%) experienced low levels of discrimination from the health officers in healthcare. The majority of PLHIV felt that they have never been treated harshly or have experienced discrimination from health workers in HIV services. Based on interviews with PLHIV, most of them were comfortable with the attitude of the health workers where they received treatment. Because they were considered friendly and cared deeply about them. As the narrative of some PLHIV below:

"...The staff is good, always remind me to take medicine before the medicine runs out..." (PLHIV 1, 30 years old)
"…There's never been bad service, if you're sick, you're treated immediately…" (PLHIV 2, 40 years old)
"...Sometimes the medicine is taken and delivered. If you don't have time to get it yourself at the primary healthcare, it was taken by my peer support from the Laskar NGO..." (PLHIV 3, 27 years old)

Only a small proportion of PLHIV admitted that they had been ignored during HIV testing, that the healthcare staffs were busy, and were seen as unfriendly in the administration of the primary healthcare. However, discrimination against PLHIV in Jember District by officers in HIV services tends to be low.

Adherence to taking ARV medication among PLHIV

Table 1. Adherence to taking ARV medication among PLHIV

Adherence Level	n	%
High	23	69,7
Low	10	30,3
Total	33	100,0

Based on the data in table 1, 23 respondents (69.7%) of people living with HIV in Jember Regency have a high level of adherence to taking ARV medication. Meanwhile, there were 10 people living with HIV who had a low level of adherence to taking ARV medication (30.3%). Based on brief interviews with PLHIV, the role of health workers from primary healthcare and assistants from the peer support of NGO Laskar was one of the important factors in adherence to taking ARV medication. The majority of PLHIV feel helped by having a peer support and the attitude of health service workers from the primary healthcare in consuming ARV medication. In addition, self-motivation from PLHIVitself also contributes to driving PLHIV in taking their medicine. As the narrative of some PLHIV below:

"...I also want to be healthy, that's why I keep taking the medicine..." PLHIV 2, 40 years old

However, there were still some PLHIV who were less compliant in taking ARV medication. PLHIV was less compliant in taking their medicine due to several reasons such as forgetting or traveling so they don't bring the medicine with them. In addition, stable health conditions of PLHIV could also be a factor for PLHIVin taking ARV medication. When people living with HIV feel healthy, they would stop taking their medicine. Another factor that causes cases of withdrawal from PLHIV, according to the peer support from LASKAR NGO, was generally caused by feelings of

laziness to take medication and visit healthcare because of the poor behavior of health workers. So, the PLHIV told their peer support to get the ARV. However, withdrawal behavior often occurs because PLHIV feels healthy rather than uncomfortable with health workers. According to another peer support, there are many PLHIV who drop out of medication or do not want to take ARV medication because of discrimination from health workers. In addition, the presence of depression and lack of support from the family for patients lead to treatment failure.

The strategy of the PLHIV Peer Support against Stigma and Lost to Follow Up

The results of interviews with PLHIV Peer Supports showed that one of the functions of peer support is to assist PLHIV in taking medicines at the primary healthcare or hospital. However, there are some PLHIV who can take medication without being accompanied by peer support.

> *"We get the medicine because usually PLHIV are also busy, I usually take their ARV medication and bring it to their house " (PLHIV peer support 1, 29 years old)*

However, even though PLHIV can take their own medicine, the peer support will still follow PLHIV to the nearest health service to accompany them while taking the medicine. So that drug-taking activities can be monitored by PLHIV peer support. Discrimination cases generally arise during drug collection or PLHIV doing regular check-up at healthcare facilities. However, based on the results of peer support interviews, it was found that the level of discrimination of PLHIV by healthcare workers, both medical and non-medical, in the Jember Regency was very rare. Several cases of discrimination were not shown in the form of activities but through expressions given by healthcare workers. This is supported by a statement from peer support.

> *"So far there have been none and it's rarely not as common as it used to be. Stigma came not in form of behavior, but in form of expression. Usually, PLHIV were looked at from top to bottom, but only seen, not gossiped about" (PLHIV peer support 1, 29 years old)*
> *"Sometimes those who did judgemental expression were not health workers, but administration worker in the registration area, or the parking attendant" (PLHIV peer support 2, 33 years old)*

On the other hand, even though PLHIV are stigmatized in the form of expression from the staff of health facilities, the majority of PLHIV do not feel burdened or objected. This is because they have grown self-confidence regarding the views obtained during treatment.

However, there were still PLHIV perceived as unaccepted in society, which is often encountered by peer support of PLHIV. Then the strategy to make PLHIV return to continue treatment was tracking them, improving their motivation, and changing the healthcare facility that comforts them.

"Usually we, as the peer support, will track the PLHIV until we meet them and invite them to be active again taking medication. The problem is he usually goes to another regency or lost contact. So, we track it down." (PLHIV peer support 2, 33 years old)
"If we go to his house, the child is not there, so we are looking for him through intense tracking until we find him. When we meet, we usually give encouragement and motivation, so they want to go back to taking medicine again." (PLHIV peer support 1, 29 years old)
"If she did not comfortable with the health worker, then the treatment will be transferred to another healthcare facility that is comfortable to her" (PLHIV peer support 3, 35 years old)

Even so, peer support as the closest people to PLHIV stated that they never acted differently, and they even tend to mingle with PLHIV.

The strategy of the health Worker regarding discrimination against PLHIV

Based on the results of in-depth interviews regarding discrimination against PLHIV from health workers, currently, the discrimination is low but adherence to taking medication among PLHIV is still an issue. The health workers have provided health services to PLHIV seriously, as stated follows:

"As for the service, it's actually the same treatment as other patients, when we apply a smile, say hello, being friendly to the patients. Especially if we look at the person in a neutral way without differentiating the disease" health worker 1, 34 years old
"When there are patients who disappear or lost to follow up, they will still be sought and monitored by primary healthcare staffs and Laskar NGO" health worker 2, 30 years old

The decrease in discrimination against PLHIV in healthcare facilities was influenced by the success of HIV/AIDS education interventions for health workers in the Jember Regency area, but in some areas that far from urban areas, interventions are felt to be lacking. It is also supported by there are service accreditation standards for HIV patient care that must be complied with by the healthcare facilities.

DISCUSSION

Stigma and Discrimination experienced by PLHIV

Discrimination according to Standard Indonesian Dictionary is a differential treatment of fellow citizens (based on skin color, class, ethnicity, economy, religion, and so on) (KBBI, 2016). Cases of discrimination such as the differential treatment of PLHIV from health workers in the Jember Regency area are low. Even though there were no statements regarding discrimination cases against PLHIV, stigma in the form of expression at PLHIV was still found infrequently. In general, medical

and non-medical personnel apart from VCT services are those who still often gave stigma in the form of perspectives. Non-VCT service sections, such as registration counters, administration, and parking, are part of the service in health facilities with cases of stigma. Based on research on discrimination of health workers against PLHIV, the highest cases of discrimination were at the front desk or receiving patients (Ng & Sullivan, 2018).

Although cases of discrimination and stigma from health workers are low, cases of stigma tend to arise from within PLHIV themselves. Self-stigma or which refers to a negative attitude towards internalized shame that is usually felt for the condition of the disease itself. Self-stigma among PLHIV arises because PLHIV feels ashamed and hopeless about their living conditions. Supported by peer support statements, the majority of self-stigma felt by PLHIV is caused because they are ashamed of their own living conditions and fear of not being cured and being unable to live a normal life such as getting married and having children. Compared to external stigma, self-stigma is more common in PLHIV. Self-stigma can indirectly affect the willingness and compliance of PLHIV in carrying out treatment (Kurniyanti, 2021). PLHIV with these conditions must be routinely assisted and given input regarding the conditions they are experiencing to prevent them from dropping out of medication.

Discrimination and Adherence to ARV Medication

Based on statements from PLHIV peer supports at the LASKAR NGO, there are many cases of people living with HIV experiencing drug withdrawal. There was no statement that discrimination could affect the withdrawal conditions of PLHIV in the Jember Regency area. The cause of drug withdrawal is that PLHIV feel healthy after taking regular drugs for months, so they decide not to take drugs again. In addition, the emergence of a feeling of laziness to carry out examinations and take drugs often causes PLHIV to stop taking drugs. This is in line with research conducted by Sholihatul (Mukarromah & Azinar, 2021) which explains that one of the causes of people living with HIV to stop taking drugs is feeling healthy and feeling hopeless. In response to this, the assistant immediately carried out a follow-up and encouraged PLHIV to continue carrying out routine treatment and accompanying them to the nearest health facility.

Even though the incidence of drug withdrawal is mostly caused by the attitude of PLHIV themselves, uncomfortable treatment such as unfriendly staff can cause PLHIV to be lazy to come to health service facilities, as a result, the peer support must make changes or transfer referrals to other health services so that PLHIV still want to carry out examinations. Thus, in general, in cases of handling treatment for PLHIV in Jember District, there is no relationship between discrimination and drug withdrawal.

The strategy of the PLHIV Peer Support against Stigma and Lost to Follow Up

The low reports of discrimination experienced by PLHIV in Jember Regency, apart from the fact that PLHIV does not care about the views of others, is because the provision of education about HIV/AIDS is very massive, especially in health care facilities. Discrimination occurs due to the lack of understanding of health workers about the spread and transmission of HIV/AIDS so after education is given, the level of discrimination decreases and is rarely found. Providing education and training about HIV/AIDS can increase the knowledge of health workers which can make them understand and not stigmatize and discriminate against PLHIV. In addition to reducing discriminatory and stigmatized incidents, providing knowledge to health workers about HIV/AIDS can increase the level of adherence to treatment of PLHIV. This is supported by research conducted by a previous study (Fitriah & Putri, 2021) which states that improving services, especially for PLHIV, can increase medication adherence and a sense of comfort for PLHIV during the treatment period. According to success stories from the peer support's side, when PLHIV stop taking medication, the assistants will track it intensely until they find PLHIV who have stopped taking the drug. When you meet PLHA again, the peer support will provide motivation so that PLHIV doesn't stop taking medication again. According to research entitled 'Identification of the Factors Causing Drop-Out of ARV in TB-HIV Patients in the Arjuna Semarang Peer Support Group', there is a relationship between the support of health workers to PLHIV (Fauziah et al., 2019).

According to the success story of peer support, when people living with HIV stop taking medication due to discrimination from health workers, the peer support will suggest changing health services that according to PLHIV are comfortable. The change of service here is not a replacement for ARV drugs, but only a change of place for treatment. This is in line with one of the AIDS prevention programs in Indonesia towards getting 3 zeroes, namely: zero new infections, zero AIDS-related death, and zero stigma and discrimination (Kemenkes RI, 2014). Peer supports as the closest people to PLHIV also mingle with PLHIV such as routinely giving medical education, routine visits, and joint activities to improve acceptance among PLHIV.

The Strategy Of The Health Worker Regarding Discrimination Against PLHIV

Based on research from the previous study (R. & Lubis, 2021), patient satisfaction could be seen based on an assessment of service quality. The quality of service depends on the method of dealing with complaints. It will be considered efficient if it can handle a quick response, and an empathetic attitude, when the patient calls directly, the response is good. The study also explained that there was a relationship between responsiveness to HIV/AIDS services and patient satisfaction. If the quality of health services obtained is good and can be maintained, it can influence and contribute to reducing the spread of HIV/AIDS. Based on success stories from the health worker's point of view,

health workers have provided good service to PLHIV by always being friendly and applying a smile, saying hello to PLHIV. Always providing a friendly attitude, can make PLHIV more comfortable during health checks. This has also been mentioned by the majority of PLHIV who said that health workers at that location had provided good service, and there was no discrimination by health workers for PLHIV, when they visited the location in person, they also saw health workers who also remembered how the compliance of PLHIV in carrying out examination and routine in taking medication. From there, there was no visible discrimination by health workers.

CONCLUSION

All respondents (100%) PLHIV stated that discrimination was low in health services in Jember District. The majority of PLHIV (69.7%) had a high level of adherence to treatment. Success in reducing stigma and discrimination in the healthcare facility is influenced by the accompanying factor of PLHIV, in which peer supports always accompanies PLHIV in carrying out medication, helping to take ARV when PLHIV was unable to visit the healthcare facility, and mingling with PLHIV so PLHIV feels less alone.

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