






Group Support's Effect on Stigma Reduction and Medication Adherence Improvement among HIV-Positive Individuals

Adistha Eka Noveyani^{*1}  , Triska Dwi Cahyani¹, Khoirunnisa Yunita¹, Anis Latifah¹, Mochammad Farhan Maulana¹, Yee Bit Lyan² 

¹ Faculty of Public Health, Universitas Jember, Jember, Indonesia

² Open University Malaysia, Selangor, Malaysia



Corresponding author: adistha.en@unej.ac.id

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ABSTRACT

An effort to reduce stigma and discrimination is still a challenge in controlling HIV cases and improving adherence to the medication among People Living with HIV (PLHIV). This study aimed to determine the factors that reduce stigma and discrimination in healthcare facilities. This research employed a mixed-method study. The population was HIV/AIDS patients in the Puger and Kencong areas. The sampling technique was purposive sampling, which resulted in 30 respondents. 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. 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 (69.7%). The success in reducing stigma and discrimination in health services was influenced by the accompanying factor of PLHIV, in which peer support always accompanied PLHIV in carrying out medication, helping to take ARV when PLHIV was unable to visit the healthcare facility, and mingling with PLHIV so PLHIV felt less alone. The research indicates that implementing peer support programs in the Jember District has significantly reduced discrimination in healthcare services and improved treatment adherence among PLHIV. It was proven by high adherence to taking medication and the low level of discrimination experienced by PLHIV. Suggesting that similar models could enhance public health outcomes in other regions.

Keyword: Discrimination, HIV/AIDS, PLHIV, Stigma, Strategy

1. Introduction

The estimated number of HIV/AIDS cases worldwide is 38.4 million, with 0.7% of patients aged 15–49 years. In the interim, the World Health Organisation anticipates that by 2021, there will be 650,000 fatalities associated with HIV and co-morbidities (WHO, 2022). The incidence of HIV/AIDS in Indonesia is on the rise. The number of HIV/AIDS cases has significantly increased over the past eleven years, peaking at 50,282 in 2019. In contrast, East Java Province has the highest number of HIV/AIDS cases, with a total of 8,935 infections (Kemenkes RI, 2020). In 2020, the number of HIV/AIDS cases was 595, and in 2021, it was 637. This figure will increase to 830 in 2023, according to data collected by the Jember District Health Office. Thus, Jember Regency is one of the districts in East Java Province with a high incidence of HIV/AIDS.

The incidence of HIV/AIDS in Indonesia is on the rise annually, with most cases occurring in men, with a percentage of 68.60% in the productive age category. The heterosexual group continues to be the primary risk factor, with 70% affected and followed by the homosexual group with 22%. In addition to offering counseling to prevent HIV transmission, Indonesia can address the high prevalence of HIV/AIDS by

conducting routine antiretroviral (ARV) treatment for those who are HIV/AIDS positive. As of 2020, the Ministry of Health reported that 142,906 PLHIV were receiving treatment. However, as many as 65,779 PLHIV discontinued treatment or were lost to follow-up (LFU), and 6,354 PLHIV discontinued treatment (Kementrian Kesehatan RI, 2021). Acquiring a stigma, one of the reasons why PLHIV has emerged is that they have chosen to discontinue treatment. Discriminatory behavior from their surroundings was observed by as many as 82.1% of female PLHIV and 88.3% of male PLHIV. The community is responsible for 40-50% of the discrimination, while 67-68% of the individuals experience discrimination from their family members and peers (BKKBN et al., 2018). In addition to discrimination and stigma from the community and family, PLHIV may also encounter discrimination from healthcare workers. It is corroborated by comparable research, which indicates that healthcare facilities discriminate against and refuse to provide services to individuals living with HIV (Lestari & Villasari, 2021). Kay et al. (2018) have also demonstrated that PLHIV receives various services in healthcare facilities. The emergence of shame and fear of discrimination can influence PLHIV to undergo routine health checks and use ARV drugs at designated health services (Kay et al., 2018).

Currently, PLHIV patients perceive that discrimination in health services has diminished, as indicated by the preliminary study of PLHIV and PLHIV peer support. However, the stigma that persists is the perspective of medical personnel towards PLHIV. Furthermore, in healthcare settings, particularly hospitals, PLHIV frequently encounters instances of direct discrimination, including the expression of sentences that can cause discomfort and the provision of criticism. Health workers' level of knowledge and perspective correlates with the stigma and discrimination against PLHIV in health services (Mahamboro et al., 2020). The lack of training on how to handle HIV/AIDS patients, the officers' low knowledge of HIV/AIDS transmission, and the fear of infection are the reasons why discrimination against PLHIV is still present in health services (Fauk et al., 2021). Most health workers and paramedics who engage in discriminatory behavior are employed in positions that are not directly related to HIV/AIDS services, such as 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 essential 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 among PLHIV in the Jember Regency area.

2. Methods

The research used a Mixed Methods Design with an embedded approach. Mixed Methods Design with an embedded approach interprets two approaches, qualitative and quantitative. The quantitative method aims to explain the differences between the variables studied, and qualitative methods aim to explore and explain more deeply the phenomena found in this 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 accidental sampling for the quantitative study and purposive sampling for the qualitative study. The variables examined in this study include adherence to taking medication for a quantitative study and strategies for reducing stigma and discrimination from caregivers of PLHIV for a qualitative study. In this study, the respondents to the quantitative study were HIV patients, and the informants in the qualitative study who were interviewed were divided into 3: primary informants, key informants, and additional informants.

The primary informants consisted of 30 HIV patients, 5 PLHIV peer support, and one health worker. The key informants were the management of the Laskar NGO and additional informants, namely PLHIV. The quantitative study's research instruments used to measure medication adherence were the Standardized Brief Questionnaire and the Morisky Medication Adherence Scales-8 (MMAS-8). The research instruments for the qualitative study were in-depth interviews to assess the discrimination and stigma among PLHIV. The researchers cross-checked the results with the PLHIV peer support. In this research, we ensure the privacy and confidentiality of HIV patients by obtaining informed consent and rigorously keeping all personal information.

Quantitative data were analyzed descriptively, and qualitative data were analyzed by content analysis. Data is presented using tables, narration, and quotations.

3. Results

3.1. Discrimination of health officers in healthcare

All respondents reported that PLHIV in the Jember Regency experienced low levels of discrimination from health officers in healthcare, with 33 individuals (100%) reporting such experiences. The majority of PLHIV report that they have never experienced discrimination or harsh treatment from healthcare providers in HIV services. According to interviews, most PLHIV expressed satisfaction with the health workers' demeanor during their treatment. It results from their genuine care for them and their well-known warmth. As the narrative of a few PLHIVs illustrates,

...The staff is good, always reminds me to take medicine before the medicine runs out..." (PLHIV 1, 30 years old)

...There's never been a 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 tiny number of PLHIV acknowledged that they had been disregarded during HIV testing, that the healthcare worker was preoccupied, and that they were perceived as unfriendly during the primary healthcare administration. Nevertheless, officers in HIV services in Jember District exhibit minimal discrimination against PLHIV.

3.2. 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

Table 1 presents 23 respondents (69.7%) of people living with HIV in the Jember Regency who have a high level of adherence to taking ARV medication. Meanwhile, 10 people were 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 critical factors in adherence to taking ARV medication. The majority of PLHIV feel helped by having peer support and the attitude of health service workers from the primary healthcare in consuming ARV medication. In addition, self-motivation from PLHIV itself also contributes to driving PLHIV to take 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 did not bring the medicine with them. In addition, stable health conditions of PLHIV could also be a factor for PLHIV in taking ARV medication. When people living with HIV feel healthy, they will stop taking their medicine. Another factor that causes cases of withdrawal from PLHIV, according to peer support from LASKAR NGO, is generally caused by feelings of laziness in taking medication and visiting 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.

3.3. The strategy of the PLHIV peer support against stigma and lost to follow up

One of the functions of peer support is to assist PLHIV in taking medications at the primary healthcare or hospital, as indicated by the results of interviews with PLHIV Peer Supports. Nevertheless, there are certain PLHIV who can take medication without the assistance of 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, despite the fact that PLHIV are able to administer their own medication, the peer support will still accompany them to the nearest health service to supervise their medication intake. This ensures that the drug-taking activities of PLHIV are monitored by the peer support. In general, discrimination cases occur during drug collection or when PLHIV undergo routine check-ups at healthcare facilities. However, the results of peer support interviews revealed that the level of discrimination against PLHIV by healthcare workers, both medical and non-medical, in the Jember Regency was sparse. Healthcare workers' expressions were utilized to illustrate numerous discrimination cases, rather than through activities. Peer support has issued a statement that backs this assertion.

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)

Conversely, the majority of PLHIV do not experience any burden or objection, even though they are stigmatized through the expression of the health facility worker due to their increased self-assurance in the perspectives they have acquired during the treatment process. Nevertheless, PLHIV was still perceived as unacceptable in society, a situation that is frequently encountered by the peer support of PLHIV. Subsequently, the approach to encourage PLHIV to resume treatment involved monitoring them, enhancing their motivation, and altering the healthcare facility that provided them with comfort.

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)

However, peer support, who are the closest individuals to PLHIV, stated that they have never acted differently and even tend to socialize with PLHIV.

3.4. The strategy of the health worker regarding discrimination against PLHIV

Currently, discrimination against PLHIV from health workers is low, as indicated by the results of in-depth interviews. However, adherence to medication among PLHIV remains a concern. The health workers have provided health services to PLHIV with the utmost seriousness, as indicated by the following.

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 success of HIV/AIDS education interventions for health workers in the Jember Regency area was a contributing factor to the reduction in discrimination against PLHIV in healthcare facilities. However, interventions are perceived as lacking in certain regions that are remote from urban areas. Service accreditation standards for HIV patients also substantiate the care that healthcare facilities must adhere to.

4. Discussion

4.1. Stigma and discrimination experienced by PLHIV

According to the Standard Indonesian Dictionary, discrimination is the differential treatment of fellow citizens based on skin color, class, ethnicity, economy, and religion (KBBI, 2016). The Jember Regency area has a low incidence of discrimination, as evidenced by the differential treatment of PLHIV by health workers. Despite the absence of any statements regarding discrimination cases against PLHIV, stigma in the form of expression toward PLHIV was still infrequently observed. Generally, medical, and non-medical personnel,

except VCT services, are the ones who continue to present stigma in the form of perspectives. Non-VCT service sections, including administration, parking, and registration counters, are included in health facilities with stigma. Health workers experienced the most prevalent instances of discrimination against PLHIV at the front desk or when receiving patients, according to research (Ng & Sullivan, 2018).

Despite the low incidence of discrimination and stigma from health workers, stigmatization is more likely to originate within the PLHIV community. Self-stigma is a negative attitude toward internalized shame that is typically experienced about the disease's condition. PLHIV experience self-stigma because of their feelings of hopelessness and shame regarding their living conditions. The majority of self-stigma experienced by PLHIV is a result of their fear of not being cured and being unable to live an everyday life, such as getting married and having children, as well as their shame about their living conditions, as evidenced by peer support statements. Self-stigma is more prevalent among PLHIV than external stigma. Self-stigma can indirectly influence the willingness and compliance of PLHIV to undergo treatment (Kurniyanti, 2021). Preventing individuals living with HIV from discontinuing their medication, they must receive consistent support and information regarding their conditions.

4.2. Discrimination and adherence to ARV medication

Many individuals living with HIV are experiencing drug withdrawal, as indicated by statements from PLHIV peer support at the LASKAR NGO. There was no indication that the withdrawal conditions of PLHIV in the Jember Regency area could be influenced by discrimination. The cause of drug withdrawal is that PLHIV experiences a sense of well-being after taking regular drugs for months, which leads them to decide not to retake drugs. In addition, the emergence of a sense of laziness to conduct examinations and take medications frequently results in PLHIV discontinuing their medication regimen. It is consistent with the research conducted by Sholihatul (Mukarromah & Azinar, 2021), which posits that individuals living with HIV may discontinue drug use due to feelings of hopelessness and health. The assistant promptly conducted a follow-up, urged PLHIV to continue with routine treatment, and accompanied them to the nearest health facility.

Even though the incidence of drug withdrawal is primarily caused by the attitude of PLHIV themselves, uncomfortable treatment, such as unfriendly workers, can cause PLHIV to be hesitant to visit health service facilities. Consequently, the peer support must either make changes or transfer referrals to other health services to ensure that PLHIV continues to desire to undergo examinations. Therefore, in most cases, there is no correlation between drug withdrawal and discrimination in the treatment of PLHIV in the Jember District.

4.3. The strategy of the PLHIV peer support against stigma and loss 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. It is supported by research conducted in 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 stops 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 be motivating so PLHIV does not stop retaking medication. 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 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 support as the closest people to PLHIV also mingles with PLHIV, such as routinely giving medical education, routine visits, and joint activities to improve acceptance among PLHIV. A previous study stated that social is the most dominant factor influencing resilience (Simanjuntak et al., 2023).

4.4. 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 exemplary 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. It 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.

5. Conclusion

All respondents (100%) PLHIV stated that discrimination was low in health services in Jember District. Most PLHIV (69.7%) had a high level of treatment adherence. Success in reducing stigma and discrimination in the healthcare facility is influenced by the accompanying factor of PLHIV, in which peer support always accompanies PLHIV in carrying out medication, helping to take ARV when PLHIV is unable to visit the healthcare facility, and mingling with PLHIV so PLHIV feels less alone. The findings suggest that integrating peer support programs into healthcare facilities can significantly improve treatment adherence and reduce discrimination against PLHIV. Health facilities should adopt these programs, train peer supporters, and monitor outcomes to enhance patient care. Policymakers must develop supportive policies, allocate funding, and create guidelines to standardize and ensure the quality of peer support programs across regions. This model could be applied to other areas to improve public health outcomes.

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