

Removing The Stigma and Discrimination for People with HIV/AIDS: The Main Role of Civil Society

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Abstract

HIV/AIDS cases in Indonesia continue to increase and have spread to all provinces in Indonesia. Bandung is one of the cities with a high number of people living with HIV/AIDS in Indonesia. As one of the areas with the highest number of reported HIV cases, the Bandung city government seeks prevention and treatment through the role of existing stakeholders. However, stigma and discrimination against people living with HIV & AIDS, now referred to as PLHIV, are still found and are difficult to eliminate. People diagnosed as contaminated with the HIV & AIDS virus often get a negative stigma. This study aims to analyze how to remove the stigma and discrimination of people with HIV/AIDS through the role of civil society. The research results show that stigma against HIV is often directed at certain minority groups and is often associated with morals and religion. Meanwhile, discrimination against people with HIV is manifested in violations of individual rights in the economic, social, and cultural spheres. The issue of stigma and discrimination against PLWHA has not received serious attention. Therefore, the role of civil society is very important because it can open a dialogue with the community regarding HIV/AIDS to dispel myths that tend to discriminate against PLHIV.

Keywords: Collaborative Governance, Handling, People with HIV/AIDS.

1. INTRODUCTION

HIV (Human Immunodeficiency Virus) and AIDS (Acquired Immune Deficiency Syndrome) have become global pandemics with various adverse effects, not only having a direct impact on health but also having socioeconomic impacts on the political field (Fauzi & Rahayu, 2019; Prabowo et al., 2020). HIV/AIDS is an infectious disease caused by the Human

Immunodeficiency Virus, which attacks the human immune system. This infection causes people living with HIV/AIDS to experience a decrease in their immune system so that they are easily infected with other diseases (Andri et al., 2020).

HIV first appeared in Indonesia in 1987. At that time, Bali was the first city to have a victim of viral infection. The victim was a tourist who came from abroad and was

living in Bali, and then the disease spread to all regions of Indonesia, including cities to villages (Uyun & Siddik, 2017). Over time, the number of HIV/AIDS case findings in Indonesia has spread to all provinces in Indonesia. Prevention is the best step that needs to be taken, and this is because the virus is no longer spreading. Moreover, patients who are infected with HIV/AIDS cases are not easy to cure (Purba et al., 2021).

A large number of HIV/AIDS cases is accompanied by negative health and non-health impacts. In terms of health, people infected with HIV will easily be attacked by various diseases that can even be classified as mild (Hidayanti, 2013). From a social perspective, people with HIV/AIDS are vulnerable to experiencing discrimination and receiving negative stigma from society because these sufferers are often considered immoral behavior difficult to accept (Fauk et al., 2008).

As a continuation of the MDGs (Millennium Development Goals) program, the SDGs (Sustainable Development Goals) still place HIV as one of the main issues of the 17 (seventeen) main goals with the target of ending the HIV/AIDS epidemic by 2030 (Amraeni, 2021). In line with this, Indonesia, through the 2019-2024 National Medium-Term Development Plan (RPJMN), targets HIV prevalence to be less than 0.5 percent in 2024. Data from the Directorate General of Disease Prevention and Control of the Ministry of Health of the Republic of Indonesia shows that the city of Bandung is one of the cities with the highest number of HIV infections, namely 12,358 people, accessed health services related to HIV/AIDS in the city of Bandung until December 2020, placing the city of Bandung in fourth place after Jakarta, Makassar and Surabaya (MOH, 2020).

According to the Director of the Global AIDS Program from WHO (1987), stigma and discrimination are the biggest/main challenges in handling the AIDS problem globally and the disease itself. This issue

was raised in the Millennium Development Goals (MDGs) declaration in 2000. One of the issues highlighted in the MDGs is the problem of the spread of HIV & AIDS which tends to increase so that the problem is not only limited to disease but also related to the issue of stigma in PLWHA (Wati et al., 2017). Although various efforts have been made, both nationally and internationally, to overcome HIV & AIDS cases, the problems of stigma and discrimination still receive less attention and are difficult to overcome/handle. The Executive Director of UNAIDS also stated that stigma is a continuous and sustainable challenge that makes the community, national and global activities constrained/hampered (Maharani, 2014).

The emergence of stigma and discrimination can be caused by a lack of community involvement in preventing and controlling HIV/AIDS, such as health counseling about HIV/AIDS (Nuwa et al., 2019). As a result, many people do not get accurate information about HIV/AIDS, especially regarding the mechanism of HIV/AIDS transmission. Discrimination against PLWHA violates human rights and does not help HIV/AIDS prevention or control (Fauk et al., 2021).

For individuals who are positively infected with HIV, living their lives will be difficult because, from a physical perspective, the individual will experience changes related to the development of the disease. The views and attitudes of the environment towards victims who generally cannot accept are afraid and labeled bad, which can impact isolation/exclusion, exclusion, and discrimination, making sufferers more depressed (Demartoto, 2018). Approximately 50% of men and women experience stigma and discriminatory treatment related to their HIV status in 35% of countries in the world. As a result of stigma and discrimination, PLWHA tends to be ostracized by their families, friends, and the wider environment (Ardani & Handayani, 2017). On the other hand, they also experience discrimination in health

services, education, and other rights. The stigma index for PLWHA indicates that 1 out of 8 PLWHA do not receive health services because of stigma and discrimination. Stigma is an attribute, behavior, or social reputation that discredits in a certain way (Katili et al., 2012).

Stigma has two perspectives, namely community stigma, and self-stigma. Societal stigma occurs when the general public agrees with bad stereotypes of a person (e.g., mental illness, addiction, etc.). Self-stigma is a consequence of stigmatized people applying stigma to themselves. Furthermore, stigma affects the lives of PLHIV by causing depression and anxiety, feelings of sadness, guilt, and feelings of worthlessness. In addition, stigma can reduce the quality of life, limit access to and use of health services, and reduce antiretroviral (ARV) adherence (Hudzaifah & Ningrum, 2021).

Several studies have shown that efforts to reduce the stigma and discrimination faced by people living with HIV & AIDS are not easy. It requires the participation of civil society, which has an important role in reducing stigma and discrimination against people with HIV & AIDS (Lalu, 2020). The role of community leaders and religious leaders in preventing and overcoming the spread. HIV & AIDS. The results of the study show that these religious leaders have contributed to overcoming the problem of stigma and discrimination against PLHIV through various religious activities (Sistiarani et al., 2018)

The results of research by Sarikusuma & Hasanah (2012) show that the forms of discrimination received by PLWHA from the environment are family rejection (shunned by the family), separation of cutlery, ostracism, and rejection from the surrounding environment such as villagers and the work environment of PLWHA. This discrimination occurs because of the fear that the environment will contract HIV and AIDS, which causes PLWHA to withdraw from the environment. PLWHA have a negative view of themselves and feel

rejected by the surrounding environment because of their illness. Hence, PLWHA has negative thoughts, feelings of hopelessness, depression, feelings of depression, and the desire to end their life. The negative label and discrimination they receive make PLWHA have a negative self-concept (feeling worthless, useless, helpless, and decreased motivation to live life and withdraw from the environment) (Sinaga & Wirman, 2015).

Based on phenomena related to stigma and discrimination against PLWHA, this paper aims to raise several important issues related to the role of civil society in reducing stigma and discrimination based on the results of a study in Bandung in 2022. Specifically, this paper aims to explain how and in what ways stigma and discrimination occur and the role and experiences of civil society groups in breaking down the stigma and discrimination against people living with HIV & AIDS. The fact shows that individuals and communities play a major role in helping PLWHA struggle with their problems, including stigma and discrimination. Many studies have shown how civil society can support PLWHA by providing the necessary information.

2. METHODS

This study uses a qualitative approach (Radzi et al., 2019). In this study, it describes an in-depth explanation of eliminating stigma and discrimination against people with HIV/AIDS through the participation of civil society, in which the explanation uses written narratives obtained from the results of observations and interviews that researchers have conducted, which is in line with the qualitative approach according to (Sugiyono, 2011). The type of research used is descriptive research. This descriptive method is relevant to the researcher's question regarding how to eliminate the stigma and discrimination of

people with HIV/AIDS through civil society participation.

Raco (2010) explains that the qualitative approach does not emphasize how many participants are used as informants but rather the quality of information, credibility, and richness of information owned by informants. Furthermore, according to Miles and Huberman, the researcher uses an interactive analysis model to analyze the data, which includes data reduction, data display, and conclusions and verification. Meanwhile, to test the validity of the data, researchers used data triangulation by checking various sources because researchers wanted to know the credibility of the data obtained from existing sources.

3. RESULTS AND DISCUSSION

3.1. Stigma and Discrimination

Stigma is a social construction of ideal social expectations manifested in social labeling that makes other people and individuals concerned look down on themselves (Goffman, 2014). Theoretically, stigma is divided into two, namely external and internal. External stigma reflects the negative social identity given by society to HIV-infected people, which results in social marginalization. External stigma is closely related to blaming HIV-infected people for their disease, misperceptions of how HIV is transmitted, irrational fears of being infected, and negative attitudes. Meanwhile, internal stigma is the belief that an HIV-infected person has about himself (internalized) as a result of the stigma inflicted on him by other people. Internal stigma is related to a negative self-image and feelings of guilt and shame (Rahman & Syafiq, 2017).

Most of the stigma that arises is related to inaccurate religious understanding; for example, people who are infected with HIV deserve to receive the curse or have been rewarded for their sins. In addition, stigma and discrimination generally occur due to a

lack of or wrong understanding of HIV and AIDS. Ironically, several health workers in Papua who have received VCT training agree with discriminatory exaggerated statements such as, "People infected with HIV are dirty; they must be rejected and punished". Most health workers also agreed with more subtle stigma statements such as "People with HIV must accept restrictions on their behavior". This proves that one-way lectures are not enough to reduce stigma (Rafi, 2018).

People's lack of understanding about the modes of transmission and treatment will lead to misinformation and create myths about HIV and AIDS. These myths then become the basis of the stigma against people with HIV positive. Some of the myths that develop in society are:

1. HIV and AIDS are diseases cursed by God. The fact is that HIV can attack anyone without discriminating against ethnicity, religion, race, sexual orientation, age, profession, or gender;
2. HIV and AIDS is a disease in the gay community, so it was originally called GRID (Gay-Related Immune Deficiency Syndrome). The fact is that currently, HIV-positive people come from heterosexual groups who have sex with multiple partners without using a condom;
3. HIV and AIDS are diseases of the west. The fact is that HIV cases were first found in Africa and America, but now their spread is very wide and can even be found in all provinces in Indonesia;
4. HIV is only transmitted through sex and only affects sex workers. The fact is that HIV can also be transmitted through the use of unsterile needles and sharing, transmission from mother to child, or unsterile blood transfusions. Sex workers are indeed one of the risk groups if they do not use condoms during sex, but apart from that, health workers also have a risk of contracting HIV if they do not carry out the procedure correctly, for example,

closing the syringe with two hands (should only be one hand);

5. HIV can be transmitted through mosquito bites. The fact is that HIV can only live in human blood and mosquitoes suck human blood instead of injecting it back;
6. Being infected with HIV means a death sentence, and a mother who is HIV positive must have a child who is also infected. The fact is that people infected with HIV if they have a healthy lifestyle, good nutrition, and a supportive social environment, will have the same life span as people without HIV. Meanwhile, babies born to HIV-positive pregnant women are not always automatically infected. With medical technology such as IVF programs, cesarean sections, or exclusive breastfeeding, the risk of babies being infected with HIV from their mothers will become smaller (Prevention of Mother-to-Child HIV Transmission [PMTCT]);
7. HIV can be transmitted through social contact such as shaking hands, hugging, using the same eating utensils, using the same toilet or pool, or being exposed to the sweat or saliva of someone who is HIV positive. HIV is only transmitted through blood, semen, vaginal fluids, and breast milk, provided these fluids do not come into contact with the air and with a balanced PH.

The stigma at the cognitive level, when manifested in the form of behavior, is called discrimination. Discrimination against HIV and AIDS is not only done to people who are HIV positive but also to people who live or are around them. Ironically, there are also family members or relatives who discriminate against HIV-positive people. Discriminatory treatment that violates these rights is generally related to the following:

1. Freedom, security, and freedom of movement, such as: forced HIV testing, quarantine, seclusion/isolation, and segregation.

2. Freedom from inhumane or humiliating treatment such as isolation of HIV-positive prisoners, involvement in clinical trials without informed consent
3. Same protection under the law: not given legal advice or services
4. Personal rights such as test results are not kept secret or made public without approval, and the name of the person infected with HIV must be reported to the authorized health agency
5. Self-determination such as people who are vulnerable to or affected by HIV are prohibited from gathering
6. The right to marry, have a family and establish relationships such as: forced abortion or sterilization, mandatory HIV testing before marriage, and discrimination against same-sex relationships.
7. Same availability of health services, e.g., shortage of suitable medicines, condoms, etc., refusal to care for or treat HIV-positive persons
8. Education such as the unavailability of information to enable people to make informed choices, refusal to provide education because of HIV status
9. Social welfare and housing, such as refusal to provide housing or social services
10. Employment such as dismissal from or discrimination at work, insurance, or other benefits limited or no HIV testing as a prerequisite for employment.

Stigma and discrimination can affect individuals' and communities' health (psychological and mental). Stigma and discrimination are also associated with avoiding testing for HIV or Sexually Transmitted Infections (STI), delaying HIV & AIDS treatment and care, concealing positive HIV status, and low physical and mental health levels. Stigma can be a source of pressure (stressor) that reduces the ability of HIV-infected people to deal with problems (coping), and discrimination hinders them from accessing health services. It needs treatment at the social

level so that people stop stigmatizing and discriminating against HIV and AIDS.

3.2. Removing the Stigma and Discrimination for People with HIV/AIDS through the Role of Civil Society

The research results in Bandung show that stigma and discrimination against PLWHA occur in society and the medical field (Rizki et al., 2020). For example, in the examination process at the hospital, there were still indications of Arab discrimination against people living with HIV or AIDS. Then, the results of the PPK-LIPI study (2019) on the access of "the unreached" migrants to health services in the city of Bandung also show that the Community Health Insurance (Jamkesmas) program for the poor does not cover medical treatment for PLHIV. This means that if a poor patient identified as living with HIV or AIDS requires medical care, the Jamkesmas program does not cover the cost of the patient's treatment. According to a source from health, the policy was implemented because it was perceived that the transmission of HIV & AIDS was more caused by high-risk behavior. Meanwhile, in Makassar, the Jamkesmas program was pursued in 2020 and includes health insurance for PLHIV; this coverage is only limited to treatment/care for "opportunistic" diseases (PPK-LIPI, 2020). The Jamkesda program (a health insurance program provided by the regional government) does not cover treatment or medical care for HIV & AIDS.

Policies like this can be said to discriminate against PLHIV. Suppose you look at the current development of the disease. In that case, people living with HIV or AIDS no longer infect people with high-risk behavior, such as needle users to consume illegal drugs, sex workers, and homosexuals. However, the disease has spread to the household realm. For example, a study in Indramayu shows that homemakers (who do not behave at high risk) have contracted the virus. They likely

contracted the disease from their husbands, who behaved at high risk. According to WHO, the transmission process at the household level is faster because, in general, wives are unaware that their husbands have contracted HIV & AIDS, so they do not use protection when having sex (Siswono, 2004). These husbands place their wives and children in high-risk situations of contracting HIV.

The roles that can be played by civil society to reduce public perceptions and behavior that lead to stigma and discrimination are at least as follows:

1. Civil society as a means of knowledge management. Communities can actively manage knowledge between civil society organizations, key populations, and communities. This means of knowledge management is broader than exchanging information because it is carried out in a structured and planned manner, primarily based on experience and pre-existing knowledge.
2. Civil society as a means of capacity building. Communities can act as a capacity-building vehicle between civil society organizations, key populations, and communities. The means of capacity building here can be exchanging experience and knowledge, for example, in the context of an organization's internal governance or developing a policy advocacy strategy.
3. Civil society as a strategic partner for HIV and human rights policy. Communities can take on the role of strategic partners, especially for the state, for policy-making related to HIV and human rights. Here, the ability to share roles and effective coordination between Coalition members becomes an important prerequisite.
4. Civil society as a responder in specific cases. Communities can respond to cases of human rights violations or reductions for PLHIV, especially those based on stigma and discrimination.
5. Civil society is the guardian of the theory of change and its development.

It also acts as a guardian of this Theory of Change. A Theory of Change is bound to the context of certain situations and assumptions and is not unlimited in age. For this reason, contextualization and re-contextualization are always needed. The Coalition is tasked with adapting this Theory of Change from time to time.

Civil society organizations working on HIV and human rights issues need to ensure that the work they are doing contributes to the movement to remove the stigma and discrimination of people with HIV/AIDS for the sake of the realization. Civil society organizations working on HIV and human rights issues need to ensure their work the work done contributes to the movement to realize a shared vision that is bigger than the goals of the institution's program or project. To that end, civil society must:

1. Continuously and mutually capacity building at the organizational level and the community level, following competence, modality, focus, and interests in various fields (research, communication, advocacy, campaigns, lobbying, legal assistance, training, counseling, health, planning and budgeting, program management, monitoring and evaluation, and others).
2. Open to mingling, learning, networking and collaborating with other organizations and communities outside of HIV issues so that HIV and human rights advocacy that is carried out becomes part of a larger movement.
3. Continuously conducting education about HIV to all parties, starting from the community and the nearest surrounding community, to realize HIV destigmatization.
4. Building and maintaining strategic and critical engagement with various parties at the national level (government, policymakers, private sector, donors) and the international level (international NGOs, coalitions, and international civil society movements).
5. Continuously building the financial independence of civil society organizations working on HIV and human rights issues so that they are more assertive in carrying out advocacy work, especially in the context of power relations with the government.
6. Encourage, support, and celebrate the champions of the HIV and human rights movement throughout Indonesia so that more and more become leaders and policymakers in various fields.

Furthermore, it is suspected that the involvement of the community and religious leaders, as respected civil society groups, can influence people's behavior. One way is through facilitated dialogue forums to support efforts to reduce stigma and discrimination against PLHIV, including mobilizing the masses to provide support and services to those infected with HIV. The existence of these figures is very important in helping to change society's negative perception towards PLHIV. Religious leaders in Malaysia and Thailand have an important role in helping reduce the number of cases of HIV & AIDS.

Religious leaders discuss matters related to HIV & AIDS through learning the Koran, which is carried out in mosques or schools. When they discussed the issue, the religious leaders did not explicitly explain the issues related to HIV & AIDS. However, they did explain it through moral teachings, especially those related to a deviant behavior that violates God's teachings, such as engaging in sexual activities outside of marriage ties. Multiple sexual partners. Thus, the message conveyed to members involved in these religious activities is that HIV can be transmitted to people who engage in sexual activities outside of marriage. Although in reality, the transmission of the virus also occurs through various media and is not related to sexual activity.

The role of religious leaders and community leaders is not only to change people's behavior and understanding but

also to increase the social solidarity of the community towards people with PLWHA. This is because community leaders provide examples of increasing people's beliefs and changing their character about the stigma of PLHIV.

4. CONCLUSION

For individuals who are positively infected with HIV, living their lives will be difficult because, from a physical perspective, the individual will experience changes related to the development of the disease. From a psychological perspective, the patient will experience stress related to other people's views, the social environment, and the social stigma against people with HIV/AIDS (ODHA). Stigma is an attribute, behavior, or social reputation that is discredited in some way. Management of

civil society stigma against PLHIV can be carried out with the participation of civil society in providing knowledge management facilities, capacity building, being a strategic partner in HIV and human rights policies, responding to specific cases, and acting as a guardian of the theory of change and development in society. To achieve this, civil society must improve organizational competence, be open to associating and collaborating with organizations, continuously build financial independence, and encourage the HIV and Human Rights movement throughout Indonesia. It is suspected that the role of community leaders and religious leaders as respected community groups can influence people's behavior. One way is through facilitated dialogue forums to support efforts to reduce stigma and discrimination against PLHIV.

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