

# CAUSES AND PROCESSES OF STIGMA AND DISCRIMINATION OF HIVAIDS PATIENTS BY HEALTH PERSONNEL IN HOSPITAL

Rahmat Aprillah D.1\*, Heni Dwi Windarwati<sup>2</sup>, Achmad Zani Pitoyo<sup>3</sup>

Master Program of Hospital Management, Faculty of Medicine Universitas Brawijaya, Malang, Indonesia<sup>1</sup> School of Nursing, Faculty of Medicine Universitas Brawijaya, Malang, Indonesia<sup>2</sup> Poltekkes Kemenkes of Malang, Indonesia<sup>3</sup>

Corresponding Author: 1\*



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#### **ABSTRACT**

Health workers' stigma and discrimination against HIV/AIDS patients affect the quality of services in hospitals. Preliminary studies show that HIV/AIDS patients in hospitals experience stigma and discrimination. This study aimed to describe the causes and processes of stigma and discrimination against HIV/AIDS patients by health workers in hospitals. The method used in this research is descriptive qualitative by conducting semi-structured interviews with ten informants from health workers who were selected using the purposive sampling technique. The interview was conducted in December 2020. It worked on elements of hospital management, doctors, medics, and admins from units that provide services for PLWHA starting from the counter, outpatient, inpatient, ER, MNE, OK, and CST Poli. The study's results illustrate that the cause of stigma and discrimination in services to patients with HIV/AIDS is due to inappropriate stereotypes, inaccurate understanding, and lack of policies from hospital management. The process or form of stigma that occurs in hospitals is as follows: Excessive use of protective measures, refusal to take medical action, non-standard services, refusal to touch in care, isolation, physical restrictions, termination of services, and verbal harassment. It is recommended that comprehensive efforts be made by hospitals to eliminate existing stigma and discrimination.



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#### 1. Introduction

Since it was first discovered in 1987 until June 2019, cases of HIV/AIDS have been reported by 463 (90.07%) districts and cities in all provinces in Indonesia. The number of reported HIV cases from 2005 to 2019 has increased yearly [5]. Pasuruan Regency, East Java Province, is ranked 8th in HIV case findings. In this district, 423 HIV cases were found in 2018. Meanwhile, until August 2019, 237 HIV cases were found [17]. The data above shows that HIV cases in Pasuruan Regency are pretty high, with an average of 35 new HIV cases per month.

Based on the increasing number of people living with HIV and AIDS (PLWHA), the need for PLWHA for health services is also increasing [18]. These health services can be in the form of care, support, and treatment in hospitals. These health facilities are agencies that play an important role in fighting HIV/AIDS. However, hospitals often stigmatize and discriminate against HIV/AIDS patients. This is indicated by the number of hospitals and doctors who do not accept HIV/AIDS patients who come for treatment. One of the causes of rejection of HIV/AIDS patients is the complexity and problem of HIV cases.

An example is the handling of HIV/AIDS patients requires the coordination of many specialists. In addition, the hospital is worried that many patients are afraid and do not want to be placed with HIV patients in the same room. However, if the hospital puts all HIV/AIDS patients in a particular room, it will lead to stigma and discrimination. Other problems that often arise are substandard care, negligence in providing care, violation of patient confidentiality, and HIV testing without the patient's consent. This shows that PLWHA often receives sub-standard medical treatment, which gives the impression of discrimination and stigma in services [16].

PLWHA and their close contacts had experienced stigma and discrimination since 20 years ago, when the first case of AIDS was diagnosed to date. This is still a severe and widespread problem in many countries. Various studies have shown that AIDS-related stigma and discrimination are widespread and occur in families, communities, workplaces, and health care systems [2]. Other studies have shown that the health care sector is one of the prominent locations of stigma and discrimination experienced by HIV-positive people [8]. Stigma prevents individuals from knowing their partner's status, accessing health services, complying with drugs, and taking preventive measures [14].

Approximately 50% of men and women experience stigma and discrimination related to their HIV status in 35% of countries in the world [7]. As a result of stigma and discrimination, people living with HIV tend to be ostracized by their family, friends, and the wider environment. On the other hand, they also experience discrimination in health care, education, and other rights. The stigma index against PLWHA indicates that 1 out of 8 PLWHA does not receive health services because of stigma and discrimination [1]. Stigma and discrimination due to HIV and AIDS are a challenge in suppressing the global pandemic. Several international institutions, such as WHO, United Nations Program on HIV/AIDS (UNAIDS), and the United States Agency for International Development (USAID), have declared this phenomenon their top priority [6].

The problems faced by PLWHA are declining physical condition and social issues such as the acceptance of negative labels and various forms of discrimination from the environment [19]. HIV and AIDS are considered a cursed disease due to deviant actions because HIV and AIDS are attached to people who commit deviations, such as prostitutes (Commercial Sex Workers), gays, free sex offenders, and injecting drug users [19]. HIV and AIDS are still considered taboo diseases that are not discussed openly with parents, teachers, the community, and health care providers. This taboo assumption makes PLWHA and their families vulnerable to stigma and discrimination, which results in reduced access to services, loss of dignity, and increased discrimination [1].

Stigma and discrimination from health workers against PLWHA can be sourced from inappropriate beliefs themselves, resulting in discriminatory attitudes when dealing with PLWHA. This emerging stigma reduces the social interaction and quality of life of PLWHA. Previous research has shown a decline in professional attitudes to caring for patients with HIV infection among health workers [22]. The stigma in the healthcare environment is a severe problem in the healthcare system. If there are patients infected with HIV and feel



stigmatized by health workers, it can affect the quality of care, safety, and quality of life of patients, as well as involvement in the care process [21].

Stigma is prejudice giving a social label that aims to separate or discredit a person or group of people with a lousy stamp or view [9]. In practice, stigma results in acts of discrimination, namely the act of not recognizing or not seeking to fulfill the fundamental rights of individuals or groups as appropriate as human beings with dignity [9]. Stigma and discrimination still often occur in people with HIV/AIDS (PLWHA) [11].

Research from various parts of the world reveals that there are three leading causes of HIV-related stigma that must be addressed in health facilities, namely: lack of awareness among health workers about stigma and its relationship to quality of care and patient safety; fear of contracting through public contact stemming from imperfect knowledge of HIV transmission; and the relationship of HIV to inappropriate or immoral behavior [12]. This stigma related to HIV also arises because of the lack of hospital service policies and national policies [14].

The fear of nurses or health workers in transmitting HIV leads to excessive steps in wearing personal protective equipment, so such actions may be time-consuming and distance the therapeutic relationship with the patient. The quality of communication and therapeutic relationships is reduced, and even discriminatory attitudes appear towards patients with HIV/AIDS [21].

The mechanisms underlying the stigmatization process, what drives stigmatization, and the impact of stigma all point to the need for potential interventions to reduce stigma in health facilities to provide quality and equitable services [13].

The results of a preliminary study at Bangil Hospital, Pasuruan Regency, using unstructured interviews with field assistants for PLWHA undergoing treatment at Bangil Hospital, Pasuruan Regency, obtained information that overall services at Bangil Hospital, Pasuruan Regency for PLWHA have improved this year when compared to previous years. The last year, when further confirmed regarding the stigma carried out by health workers, it was revealed that there are still services that seem to stigmatize PLWHA in the field. This fact encourages the need for more in-depth research with qualitative methods. This study aims to describe the causes and processes of stigma and discrimination against HIV/AIDS patients by health workers in hospitals.

#### 2. METHOD

This research was conducted with a qualitative descriptive method. The method of collecting data is semi-structured interviews with ten informants who were selected using a purposive sampling technique. Interviews were conducted in December 2020, performed on elements of hospital management, doctors, medics, and admins from units that provide services for PLWHA starting from the counter, outpatient, inpatient, ER, MNE, OK, and CST Poli. The selection of these informants is considered to have represented all services for PLWHA at Bangil Hospital to dig deeper into the causes and processes of stigma and discrimination in existing services.

The data collection results through interviews were then processed for analysis using content analysis and interpretation of theoretical themes. The process of verbatim transcription was carried out on the results of the interviews, then the process of grouping similar data was carried out and ended by finding the themes of the data.

#### 3. RESULTS

The findings of this study are presented according to the grouping of informants' answers based on two main themes, namely the underlying causes of stigma and discrimination and the process or form of stigma and discrimination that occurs in PLWHA services. Furthermore, the results will be presented based on the existing categories.

## 3.1 Causes of stigma and discrimination

## 1. Inappropriate stereotypes

"But when I say in other places, there are many people who do not know like this... yes, the father and mother are HIV, their children must be HIV because they may not know that" (MD8122020)

"Come on, do not get close to people with HIV or for example, that is the environment, never mind, there is no need to approach singers like that, later life will be like this, right there are people like that" (MD8122020)

"But if we have a patient who has a tattoo, we must think, it is like that... which is weird" (UR29122020)

"In the past, maybe yes... But... personally, yes.. That is probably me, the term is like underestimating the patient... maybe like this patient means...(HIV stereotypes with a bad background)" (MR30122020)

"So if it was treated at the beginning because I note that I still think HIV is a disgusting disease like that, a doctor, right?" (PCW30122020)

Some of the informants interviewed above stated that they had experience with stereotyped forms of groups or communities and also people with HIV that underlie the emergence of stigma and discrimination in services at work in hospitals.

#### 2. Incorrect understanding

"Your thoughts, sir... If you think seriously, it is like being afraid of getting infected, actually... afraid of getting infected... Moreover... in the past... the stigma of seeing an HIV patient was like... What disease, sir" (UR29122020)

"The mindset used to be... In the past, HIV AIDS was... even if we had it... For example, shaking hands with sweat got infected, yes... If later, for example, we scratched him, there was a slight wound, and we shook hands with the infection... even though the person is those with HIV AIDS do not have wounds, they gush blood" (PW29122020)

"Yes... It is very different, sir.. If we were first, maybe our understanding was also lacking" (RPL29122020)

"It is a long process, first we are afraid... How about it, how do we go about the operator, how do we go about the process, the medical waste flow, the... dirty linen line that first scared us... (laughs) Not yet... yes, not yet. there is a transfer of knowledge... First, we must be afraid" (OE29122020)

Insufficient and wrong understanding is one of the causes of stigma and discrimination related to HIV/AIDS services by health workers, as shown from the results of the interview above.

## 3. Lack of Policy



"If we only, if in fact, the standard is... NIC, Nurse In Charge... There is standby which will filter to what poly to which poly ... But still not available" (LA10122020)

"None... Not yet... (There is no HIV/AIDS training for counter staff yet)" (LA10122020)

"In the past, it was like it did not open.. If it used to be like a cover-up... what hurts?" (RUH12122020)

"For now we are using the usual flow, so no.. not the same as before; what if it used to be... if it used to be the one who held it, for example, it had to be a senior like that, sir... yourself, if the others were like fear or what?" (RPL29122020)

"Well, that is one of them, then yes it looks like the system, sir.. the system is also now better for the problem of PLWHA, starting from the flow we receive from MNE like what, then what we also do not break communication with.. with what... CST, I see, so we give each other information, for example, we have patients here, CST also knows, in CST if you want to enter we also know, the system is well organized. (RPL29122020)

Hospital policies that do not support services for people with HIV/AIDS have caused health workers, in this case, doctors, nurses, midwives, and administrative staff, to stigmatize and discriminate in services as described from the results of the interviews above.

## 3.2 The process or form of stigma and discrimination

1. Overuse of protective measures

"Except for that patient, if we help with delivery, for example, there is this patient, who comes with a complete opening, stage 2, now that is us, like it or not, we want to help at the MNE Doc... So we call it more PPE (PPE and special disposable linens))" (MR30122020)

"The point is the same... Only... maybe the PPE is all that is needed (above standard)" (RUH12122020)

"Then, we will prepare the treatment for the functional area below, to prevent it, apart from using a hogie, below that we treat the underpad so that there are no droplets scattered, even though above is safe, the bottom is safe too... Then for the bed we use for the PLWHA, we have a set starting to stretch to We will not use the time in the recovery room for other patients" (OE29122020)

"If it is in front of you, it is not pure HIV, and if you have done HIV surgery, we will do a cleaning when (room disinfection plus fogging and 1-hour pause for other operations) we... we... the term disinfectant and others like that" (OE29122020)

"For non-PLWHA it is usually at least... just an apron, if it is new.... so the level is possible, the medium level is maybe yes, for non-PLWHA, if PLWHA is usually complete" (PKS11122020)

"So we wear double operating gloves, even if we only give injections if in the technical guidelines, even if we do not wear surgical gloves, we can also inject... But to patients with a clear diagnosis of HIV, we inject using double surgical gloves., measuring blood pressure—wear surgical gloves, so basically touching the patient, we have to use the protection which is now... too much... so then yes, wearing a mask oh so and so there is TB, there are coughs of all kinds, even double the mask Even though the patient is outwardly ordinary, there are no external injuries, but still because he is HIV, we are direct, what is clear is that he has

to be double-protective, that is if he was a doctor" (PCW30122020)

From the interview results above, the use of excessive protection measures such as the use of double or more handscoen, the use of personal protective equipment (PPE) above the recommended level, and carrying out excessive sterilization and disinfection procedures in the field. Moreover, there are also facts from the interview results which illustrate that universal precaution (UP) is actually weaker in carrying out non-HIV/AIDS cases which should be treated the same as cases with HIV/AIDS.

#### 2. Refusal to take medical action

"Yes, that was when a patient was found, for example, with an STI or with TB, they did not want to do the PITC themselves, they delegated it to the POLI VCT like that, he should have been ready for that, or have we had a patient. not done here... like that and was referred to another hospital" (MD8122020)

"In the past, those at the Bangil Hospital in the ER, if there were patients, Mrs. Darmi fled, all of the HIV patients ran away. No one wants to serve anymore, just look around" (MD8122020)

"Yes.. yes.. But still.. because at first the term from anesthesia was also not acceptable, then the SpOG was also disapproved of (doing SC), so the term still cannot be handled here in the past" (MR30122020)

"In the beginning, it was the same, and if there were HIV patients, they would be referred" (RPL29122020)

"No... We do not dare.. not yet.. still... still.. someone is... If there is a patient (operation) we will refer him" (OE29122020)

The refusal of medical action described in the above interview results in the form of refusal of examination, light action to the implementation of surgery on patients with HIV/AIDS.

#### 3. Service is not up to standard

"For example, if it is found in the poly or room, it will be counseled to a counselor on the VCT team. Actually, we have a PITC, but sometimes due to lack of confidence, we finally call Mbak Sri (CST Poly HIV Counselor) VCT Team" (MD8122020)

"If the teams are different... if you mention the teams in other health workers are different... someone checks them from afar... see skin pain, like this, especially HIV, it gets farther away... like that there... to that, huh ,,, it's different for each person... like that" (MD8122020)

The service does not meet the intended standard from the results of the interview above in the form of services that are not under the existing service SOPs.

## 4. Refusal to touch in care

"Ask for help, suddenly I do not care... for a second, Ma'am... intermittently... like that... immediately like that... I was ignored... sometimes I calmed my patients... it was not ignored...because there was a lot to do, so it was not true, ma'am. if you have to hold me, I do not want to" (MD8122020)

The interview subject informant described his experience when he had to calm patients who seemed not appropriately handled because medical officers did not dare to provide services to PLWHA.



#### 5. Isolation

"It is like we have to isolate the patient... we have to isolate earlier... Between the PLWHA patient and the other patient... There is a bit of a gap between 2 beds or three beds in the past, sir" (UR29122020)

Isolation that occurs according to the results of the interview can be in the form of room or bed isolation, even if it is for the convenience of the patient concerned, other patients, or the comfort of the officer.

## 6. Physical restrictions

"For example, at the counter and then at the polyclinic if there are HIV patients, the seats are different, it used to be like that, meaning it is a bit far away, do not get close to officers like that" (MD8122020)

"We are also keeping our distance, but we are not conspicuous to stay away from them, and there is no intent to harm them. Look at them, when they come, we treat them as ordinary patients, there is no difference" (LA10122020)

Physical limitations arise due to stereotypes that appear in PLWHA.

#### 7. Termination of service

"Like the stories from patients who are actually... like that... Mom, I was left... I was ignored... as if it were like that" (MD8122020)

Termination of services arises because health workers are confused and afraid to provide services quickly so that the PLWHA they serve feel that the services provided to them are terminated compared to other patients.

## 8. Verbal harassment

"Because in my experience there was a post-MRS patient, on the patient's status the name of Doctor Darmi CST was written, meaning HIV, it was written like that, and the code was not written, it was written HIV... then I immediately asked, do you want to go to... CST yes... dr. Darmi.. then he got angry, this should be a secret" (LA10122020)

Verbal harassment that arises in the service is caused by internal factors of the patient and the patient's family, who are very sensitive to the illness they are suffering, causing misinterpretations and emotions.

## 4. DISCUSSION

The study's results illustrate that the causes of stigma and discrimination in services to patients with HIV/AIDS are inappropriate stereotypes, inaccurate understanding, and lack of policies from hospital management.

Cases of HIV/AIDS, initially found in homosexual groups, have now spread and reported to everyone who could potentially be infected with the HIV. The risk of transmission seems to have grown not only in key populations, namely FSW (Women Sex Workers), MSM/Homosexual, TG (Trans Gender), IDU (Injecting Drug Users), and WBP (Penitentiary Inmates). Still, it has spread to all groups of society. Available data show that HIV/AIDS has been reported to increase among housewives, even children or babies whose mothers are infected with HIV [15].

Stigma appears mainly related to the presence of inappropriate stereotypes [10]. This occurs because of the

perceived HIV with wrong or immoral behavior [12]. In addition, stigma and discrimination generally happen due to an inaccurate understanding of HIV and AIDS [10], resulting in fear of contracting HIV through public contact [12]. This stigma related to HIV also arises because of the lack of hospital service policies and national policies [14]. The stigma that is on a cognitive level when manifested in behavior is referred to as discrimination. Discrimination against HIV and AIDS is not only carried out on PLWHA but also on people who live or are around them [10].

The act of stigmatizing or stigmatizing occurs through several different processes such as [9]:

- a. Actual (actual) or experienced (experienced) stigma: if some people or communities take actual actions, both verbal and non-verbal, that cause other people to be distinguished and excluded.
- b. Potential or perceived stigma (felt): if the act of stigma has not occurred, but there are signs or feelings of discomfort, people are less likely to access health services.
- c. Internal stigma or self-stigmatization: if a person judges himself as "unentitled" or "unliked by society." The stigma process is not singular; several of these processes can coincide and can be dual stigmatization (e.g., "whom abusers" as well as "IDUs").

The results of this study also illustrate that the process or form of stigma that occurs in hospitals is in the form of:

- 1. Use of necessary Actions excessive protection
- 2. Refusal to take medical action
- 3. Service is not up to standard
- 4. Refusal to touch in care
- 5. Isolation
- 6. Physical restrictions
- 7. Termination of service
- 8. Verbal harassment

According to existing regulations, hospitals must provide care, support, and treatment services for PLWHA. The hospital is a referral network for first-level health facilities (FKTP) or Puskesmas in delivering services for PLWHA. But in reality, hospitals can also be a place for people living with HIV to experience stigma and discrimination. This discrimination can include poor levels of health care, denial of care or treatment, isolation, labeling or unique identification of a person as HIV positive, breach of confidentiality, use of negative language or body language by health care staff, and restrictions on access. To a health care facility. Concerning this issue, in 2008, 3 of the seven provinces included in this study had regional regulations explicitly addressing issues related to HIV and AIDS, namely the Special Regions of Jakarta, Bali, and East Nusa Tenggara. The rules mentioned above regulate the provision of non-discriminatory accessible health care facilities for PLWHA. For example, Article 17 of Jakarta Provincial Regulation No. 5/2008 on HIV and AIDS clearly states: "Every health care provider must provide services to all people in need without discrimination and must maintain the confidentiality of data regarding PLWHA" [20].

However, the survey found that discrimination still exists in health care facilities where PLHIV respondents claim to have received "different treatment" because of their HIV status. From previous studies, as many as 57 percent of PLWHA overall, including 59 percent of male PLWHA respondents and 53 percent of female PLWHA respondents, reported experiencing discrimination in health care facilities. The percentage of PLWHA who report experiencing discrimination in health care facilities by sex and the type of discrimination encountered is illustrated in Table 1.1. below [20].



**Table 1.1.** PLWHA who are discriminated against in health care facilities according to the type of discrimination they face and their gender (%)

<b>;</b>		
Men	Women	Total
41	40	41
12	7	11
11	9	10
9	7	8
9	4	8
7	6	7
7	5	6
5	4	5
4	2	3
2	2	2
1	1	1
1	1	1
	41 12 11 9	41 40 12 7 11 9 9 7

The forms of HIV-related stigma that have been reported through previous research are:

- a. Stigma through labeling on PLWHA, including giving a sign on the bed for PLWHA [14]; giving a unique code to the status of PLWHA patients [11].
- b. Verbal stigma, including mentioning HIV disease in a loud tone [11].
- c. Non-verbal stigma, including what is done when health workers deliberately limit looking at PLWHA patients [4].
- d. Stigma through actions taken indirectly to PLWHA patients, including burning clothes of HIV-positive patients after they are no longer used; excessive use of personal protective equipment [14]; distinguishing waste disposal sites from PLWHA patients [11].
- e. Stigma through actions taken directly to PLWHA patients, including avoiding touching and even avoiding seeing HIV-positive patients [14]; providing inadequate/slow health services in following up on actions against PLWHA; different services (difference in treatment of patients when carrying out treatment even though PLWHA patients have chosen the VIP room, feeding under the door, bed sheets are not changed); and isolate PLWHA patients without medical reasons; and perform medical actions without giving informed consent before the procedure is performed (for example performing a vasectomy procedure forcibly on a patient who gave birth by cesarean section and blood tests) [11].

From the results of the research above, which have described the causes and processes of stigma and discrimination related to HIV/AIDS services, the hospital management steps that can be taken to eliminate stigma and discrimination to improve the quality of service quality and patient safety that can be taken are as follows:

- 1. Formation of the comm hospital director. The committee is tasked with designing, directing, monitoring, and evaluating the management of patients with HIV/AIDS [14].
- 2. Always involve partners in treatment or care efforts to restore social relations and reintegrate PLWHA into society [1].
- 3. Educational interventions emphasize common values of human dignity and compassionate care [21].
- 4. Sending health workers to attend training regularly [16].
- 5. Increase counseling activities, both individual, group, and mass, in providing more information about HIV testing and care and treatment of PLWHA [3].
- 6. Involving the role of NGOs and outreach workers in providing support for PLWHA in gaining access to counseling, care, and treatment [3].
- 7. Provide and reward health workers who successfully treat PLWHA [3].

- 8. Establish regulations in the form of SK, Guidelines, and Guidelines, as well as standard SOPs to support efforts to eliminate stigma and discrimination against PLWHA, accompanied by technical guidance and continuous monitoring [11].
- 9. Make an MOU between the hospital and other stakeholders for clarity on the division of job descriptions [16].
- 10. Provide quality support facilities to provide test, care, and treatment services for patients with HIV/AIDS, in the form of examination reagents, personal protective equipment, and medicines [11].
- 11. Advocating with the health office and hospital directors in improving the quality management program for health services in hospitals to increase the perception of health workers towards PLWHA and eliminate stigma and discrimination [11].

#### 5. CONCLUSION

The results of the study illustrate that the causes of stigma and discrimination in services to patients with HIV/AIDS are: Inappropriate stereotypes, inaccurate understanding, and lack of policies from hospital management.

The results of this study also illustrate that the processes or forms of stigma that occur in hospitals are: Excessive use of protective measures, refusal to take medical action, non-standard services, refusal to touch in care, isolation, physical restrictions, termination of services, and verbal harassment.

It is recommended that comprehensive efforts be made by hospitals to eliminate existing stigma and discrimination.

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