

# Stigmatization of Household Mother with HIV/AIDS in Tulungagung District, East Java, Indonesia

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12

## **Stigmatization of Household Mother with HIV/AIDS in Tulungagung District, East Java, Indonesia**

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**Abstract.** Stigma is an assessment of behavior or character that is not fair or gives a negative title to a particular person or group that aims to isolate. The study aimed to explore the experience of homemakers with HIV AIDS about the stigma experienced by health workers. A qualitative method with a phenomenological approach was applied in this study. Eleven informants were selected from the Tulungagung Regency area. We conducted the data collection using the in-depth interview; data analysis was carried out according to Collaizi's steps. The results of this study are information about the stigmatized experience of PLWHA, namely

1) Writing identity with a specific code, 2) HIV status of informants was discussed by nurses at the hospital, Using gloves and masks when handling, even if only limited to checking body temperature, 3) Separation of hospitalization rooms while undergoing hospitalization, 4) Not given health services because of the unavailability of drugs when sick, This research shows that there is still a stigma received by PLHIV from health workers so that further treatment of stigma in health care institutions is needed to improve the professionalism of health services, health workers in health care agencies must be able to provide fair services to every patient who needs health care and maintain patient privacy.

**Keywords:** Health coaching, health promotion model, adolescent, behavior

3

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### **INTRODUCTION**

17

Human Immunodeficiency Virus (HIV) is a disease that attacks the immune system and affects susceptible to various conditions (1-2). This HIV carries genetic material in ribonucleic acid (RNA) to cause a decrease in T-CD4 cells. One in 4 people is diagnosed with HIV when CD4 <350 cells/microliter (3). HIV AIDS, in its journey, will experience 3 phases (3). Based on a report from the AIDS Commission of Tulungagung District, it was found that there was an increase in the number of new people living with HIV AIDS every year in 2015 with 257 cases, 2016 with 324 cases, 2017 with 324 cases and 2018 with 319 cases (4). The

male group currently still dominates with 55%, and the age group 25-49 years is the highest age group, with a total of 1585 patients (5).

Another problem that can be found in HIV is the stigma against PLWHA (6). Stigma is an assessment of behavior or character that is not fair, revealing stigma is an attitude or emotional reaction that appears in the community (7). In this study is aimed at PLWHA by health workers. Preliminary studies conducted by researchers showed that homemakers with HIV AIDS in Tulungagung had experience stigmatized by health workers.

An effort on preventive is essential and most effective since it can reduce the risk of HIV transmission. In addition, this strategy avoids someone from being exposed to the risk of transmission (8). A previous study revealed that HIV patients with a better effort on treatment therapy of Antiretroviral therapy (ART) increased PLWHA life expectancy (9).

Handling HIV-AIDS problems is not enough only on health aspects, but also refers to social aspects (10). This is because HIV-AIDS sufferers not only experience health problems but also experience social issues (11). the stigma of PLWHA is one of the social issues received by patients in the form of verbal statements and discrimination (12).

Stigma occurs not only from people in the surrounding environment but also often carried out by health workers, who have an essential role in advancing in the field of health services (13). Health workers should provide services to all people in need without distinguishing health and social status (14). Especially for nurses, they must also have value and self-confidence to provide services, including PLWHA. Anxious feelings and worries that the nurse has can do stigmatization without the nurse noticing (15)

The stigma can have an impact on many things starting from the onset of depression, psychological distress, and anxiety, which will eventually lead to PLWHA being unable to achieve its independence (16). Other research shows that PLWHA is reluctant to open an identity because it cannot be accepted by its environment so that most PLWHA has a disruption of social interaction with the surrounding community (17). Disparities occur in several places that cause PLWHA to get worse with its health status, which is reflected in the treatment received by PLWHA in the work environment and living environment (18).

The purpose of this study is to explore experiences related to the perception of PLWHA towards the stigma they experience. This research is expected to provide ideas for further research related to the perception of PLWHA towards the stigma experienced. It can be used as a reference to eradicate stigma to PLWHA.

## OBJECTIVE

This study aims to explore the stigmatized experience of PLWHA received from health workers in health care agencies in Tulungagung Regency, East Java.

## METHOD

<sup>15</sup> This study used a qualitative method with a phenomenological approach. Data collection was carried out by in-depth interviews and collection of documents in the AIDS Commission in Tulungagung Regency. Informants in this study were housewives with HIV AIDS who had experience stigmatized by health workers. The sampling method used was purposive sampling. The study was conducted in Tulungagung Regency involving 11 informants. The results of in-depth interviews were collected and then continued with a Focus Group Discussion (FGD) by involving HIV program holders in health service agencies. HIV program holders in the Health Office of Tulungagung District, AIDS Commission of

Tulungagung District (KPA), and community leaders. The inclusion criteria in this study were housewives with HIV AIDS who had the experience of stigma from health workers, the exclusion criteria of this study are homemakers with HIV AIDS who experience stigma from other than health workers.

This research has received ethical approval from the ethics commission of health research in the faculty of nursing Universitas Airlangga. The letter-number passed the ethical review "1374-KEPK" Universitas Airlangga.

## RESULTS

The results of this study are the breakdown of information about the stigmatized experience of PLWHA divided into four dimensions including Labeling reflected in the form of identity writing with a specific code on the newborn baby box and informant's HIV status discussed by nurses in the hospital as a form notice to other nurses:

*"It means that the officer is always writing B29 code ... Yes, the code in the baby box is written like that. And what I feared was that if my siblings understood health, right, how come there was writing. That's not good, bro, you asked. Even though his son doesn't understand his parents' problems, how's that...." (I7)*

The stereotype illustrated by nurses who consider that the son of an HIV-positive informant who is the child is HIV negative so that nurses use gloves and masks when handling even if they are only limited to examining body temperature.

*"..... My child was examined twice for the test. The second is also negative, right. Then my child was sick. I was hospitalized at the RSI. Well, at the time, I didn't know because information about my identity was already known to the RSI. Finally, his view may be that all my family is like that. Well, when treating my child, the nurse all used masks. Use these gloves even if you only check that it's hot like that ....." (I1)*

Separation of forms experienced by informants is the separation of inpatient rooms while undergoing inpatient care at home.

*"..... But at that moment we were indeed placed in the room ... isolation room ....." (I1)*  
*"..... because my neighbor is a journalist mas. Saying that the sub-district office said I was HIV ... " (I5)*

The form of discrimination experienced by informants is not given health services for reasons of unavailability of medication when sick, not getting good service when hospitalized (shouted), unclear service flow between one health institution and another (informants felt they were swayed when they were immunizing their HIV negative children, obtaining improper hospital facilities (bed cover were never replaced, while other patients were replaced).

*"..... Then I felt that the nurse knew that my family was like this. So he seems to be afraid. I immediately said that my child is HIV negative ... " (I1)*

*"..... Because at that time, my husband was sick, I took it to the health worker who did not want to give medicine. He said he did not have medicine..." (I3)*

*"..... during my child's immunization, the village midwife told the Puskesmas, I came to the Puskesmas and then I was told to go to the hospital ... " (I8)*

*".....The bed cover for the husband's bed at the hospital was never replaced, while the other patients were replaced...." (I1)*

## DISCUSSION

The results found that health workers have a different perspective on the use of personal protective equipment to prevent HIV. Health workers said that they did it to ensure conditions safely from possible transmission of the disease owned by patients other than HIV (19). Community leaders who are in the village explained that health education on HIV had been carried out throughout the whole Tulungagung Regency. However, in reality, many who are unwilling to bathe the bodies of HIV patients. Also, some of them told the public about HIV issues to others. However, foster awareness and understanding of society are not accessible because there are still many people who think that ODHA is people who "endanger" them. Holders of HIV programs at the Health Office and Puskesmas regularly monitor PLHIV in their area, monitoring is done to ensure that PLHIV routinely consumes ARVs and motivate PLWHA to get a better life in terms of health and social life. However, there are still many PLHIV who close themselves and keep their status confidential for fear that if their condition is open, they will get a rejection from the community.

The AIDS Commission has made efforts to protect PLWHA from acts of stigma by building communication with community members, the Tulungagung District Government, health service agencies. However, in reality, stigma still occurs with decreasing intensity every year.

This research is in line with the study of Cuca, which states that the stigma of women's groups is the highest group experiencing stigma because women have low social capital (20). Other research indicates that nurses carry out stigma in health care units on the dimensions of labeling and stereotypes (16). The results of this study are in line with research from Harapan which explains that the stigma that occurs in health care units is caused by location, the experience of health workers, and knowledge of health workers about HIV (10)

## CONCLUSION

This study revealed that stigma against PLWHA is still found in the field. Therefore, It needs some solutions to solve problems by increasing the understanding and knowledge of health workers about stigma. Health workers in health care agencies should be able to provide good services to all patients without distinguishing the patient's health status. Maintaining patient privacy must be carried out to protect HIV patients from all forms of stigma that occur; HIV patients have different adaptive abilities to their HIV status. Patient's HIV status extensively should be preceded by a good understanding of HIV from family and community to avoid stigma.

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