

## Experiences of Students with HIV in Facing Social and Family Stigma in Swadiri Institute Environment

Yedya Kezia Valentine Suwarso<sup>1</sup>, Hasmi<sup>2\*</sup>, Novita Medyati<sup>3</sup>, Arius Togodly<sup>4</sup>,  
Rosmin M. Tingginehe<sup>5</sup>, Sarce Makaba<sup>6</sup>

<sup>1</sup>Master of Public Health Study Program, Faculty of Public Health,  
Cenderawasih University of Jayapura

<sup>2,3,4,5,6</sup>Departement Master of Public Health Program, Faculty of Public Health,  
Cenderawasih University of Jayapura

**Corresponding Author:** Hasmi, [hasmiuncen@yahoo.co.id](mailto:hasmiuncen@yahoo.co.id)

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### ABSTRACT

The aim of this research is to find out how students with HIV experience facing social and family stigma within the Swadiri Institute environment. This research uses a qualitative research type of phenomenological design. Students living with HIV face various challenges, ranging from emotional reactions such as fear, shame, and depression, to social pressure due to stigma and discrimination. HIV transmission among students is largely influenced by risky sexual behavior, especially after consuming alcohol, as well as low understanding of reproductive health. However, support from family, peers and the campus environment plays an important role in helping them deal with this condition. This support not only provides emotional strength, but also encourages adherence to treatment, especially regular ARV consumption, so that lives.

## INTRODUCTION

HIV/AIDS is a significant public health problem in Indonesia, with the number of cases continuing to increase from year to year. The age group of teenagers and young adults (15–24 years), including students, is the group most vulnerable to HIV exposure (Indonesian Ministry of Health, 2023). This is influenced by unstable emotional and sexual development factors, lack of education regarding reproductive health, as well as the influence of the social environment and mass media which can encourage risky sexual behavior (Salsabila & Khoiriyah, 2019). This condition is exacerbated by the lack of understanding and good attitudes towards HIV/AIDS, especially among the younger generation (Fauziah, 2017).

Papua is the region with the highest HIV burden in Indonesia, with HIV prevalence in adults reaching 2.3%. The main challenges in treating HIV include prevention efforts, case detection, connecting positive sufferers to treatment services, maintaining continuity of treatment, and reducing the number of viruses. In 2022, it was recorded 20,441 HIV cases, with 5,774 cases in the adolescent age group (15–19 years) and 11,882 cases in the 20–24 year age group. Jayapura City is in second place with the highest number of cases among 28 districts/cities in Papua Province, after Nabire Regency, with a total of 1,987 HIV cases (Resubun, 2021).

One of the challenges in dealing with HIV/AIDS is stigma and discrimination against HIV/AIDS sufferers (PLWHA). HIV-related stigma and discrimination remain a major obstacle to effective responses to HIV worldwide, with national surveys showing that discrimination against treatment for people living with HIV still occurs in various aspects of life (Unaid, 2011).

The Swadiri Institute (ISWA) is one of the private campuses in Papua, especially in Jayapura, where four HIV positive students were found out of a total of 130 examined, indicating that the campus is also a space for the spread of HIV. The four students come from diverse cultural and social backgrounds, with some of the students only finding out about their health status after being examined on campus (Institut Swadiri, 2025). Students are in a position that is very vulnerable to stigma and discrimination, both from the campus environment and their families.

Stigma towards PLWHA is still a big challenge, reflected in cynical attitudes, fear, exclusion, and discrimination which can cause severe psychological stress and social isolation (Aris Tristante et al., 2022). The Eastern Region of Indonesia, with its diversity of cultures and social backgrounds, may face particular challenges regarding society's perception of individuals living with HIV-AIDS. Stigma and discrimination against HIV-AIDS sufferers can include cynical attitudes, excessive fear, exclusion and unfair treatment in various sectors.

## LITERATURE REVIEW

### *Definition of Human Immunodeficiency Virus (HIV)*

According to Kummar in (Yuliyanasari, 2017) AIDS (Acquired Immune

Deficiency Syndrome) is a collection of disease symptoms that arise due to HIV retrovirus infection. This condition is characterized by a weakening of the body's immune system, which can trigger the emergence of opportunistic infections, secondary neoplasms, and various other neurological disorders. HIV is a virus that infects and destroys white blood cells in the body. This infection causes a decrease in the human immune system because the virus attacks cells that play a role in the body's defense (Ahmad Yusuf Armanda et al., 2024).

Several factors can cause HIV transmission, and the most common or dominant is through unprotected sexual intercourse (Marlinda & Azinar, 2017), Blood transfusion is one of the routes of HIV transmission with the highest risk, reaching 100% (Bappenas, 2017). Medical personnel are at risk of contracting HIV if they are pricked by a needle contaminated with the blood of an infected patient, or if blood or body fluids from an HIV positive patient get into their eyes, nose or open wounds on the skin (Hariyawanti et al., 2020). HIV can be transmitted to other people if body fluids from an infected individual enter another person's body. However, not all types of body fluids that move have the potential to transmit the virus (Bappenas, 2017). Pregnant women infected with HIV have the potential to transmit the virus to the fetus they are carrying, with a risk of transmission between 20 and 50% (Bappenas, 2017).

### *Theory Stigma*

The stigma theory was put forward by Goffman in (Ninef et al., 2023). According to Goffman, stigma is any form of physical and social attribute that reduces a person's social identity, disqualifying that person from being accepted by others. Stigma makes someone different from others such as being worse, dangerous, or weak. Goffman divides stigma into three, namely: Stigma against bodily defects, Stigma against someone's bad behavior, Tribal stigma.

According to Goffman, individuals who do not meet social standards are considered abnormal and experience stigma. Over time, stigmatized people can agree with this negative view of themselves, which makes them feel like they have failed and become increasingly marginalized in social life (Danar Dwi Santoso, 2016).

### *Definition of Stigma*

According to the Big Indonesian Dictionary, stigma is a negative characteristic found in a person's personality due to the influence of their environment. According to Goffman in (Dayanti & Legowo, 2021), stigma is a label that damages a person's self-image and has a big impact on his personality, which ultimately makes it difficult for him to behave as usual. Stigma is the negative labeling of certain individuals or groups, which can have a negative impact on their mental health. This stigma can cause discrimination and prevent them from achieving their life goals, such as obtaining job opportunities and the opportunity to live independently and safely (Hartini et al., 2018).

### *Stigma Social*

According to Erving Goffman in (Agustang et al., 2021) Social stigma is a label given by society to an individual, where the individual is associated with stereotypes and negative assessments. As a result, the person tends to be treated differently or considered abnormal. This social stigma is part of prejudice which often triggers discrimination and unfair treatment towards someone.

### *Family Stigma*

According to (Larson & Corrigan, 2008) Family stigma includes stereotypes such as blame, feelings of shame, and perceptions of pollution. This stigma is not only directed at individuals living with HIV, but also impacts the family members who care for them. According to Link & Phelean in (Muawanah, 2021) family stigma is the relationship between family members and the sufferer, where the stigma imposed on the sufferer is also imposed on the family.

According to (Larson & Corrigan, 2008) the family stigma process can affect individuals negatively in various forms, such as family members who tend to avoid social interactions, waste energy and resources, hide secrets, and face discrimination at work or in home life.

### *Impact of Stigma*

According to Phuhl in (Simanjuntak, 2005) there are several impacts of stigma, namely: Stigma makes it difficult for individuals to seek help, Stigma makes it difficult for individuals to restore normal life because it causes the individual to withdraw from society, Stigma causes discrimination so that it is difficult for the individual to get accommodation or work, Society can be harsher and less humane, The individual's family will feel more insulted and disturbed.

### *Framework of thinking*

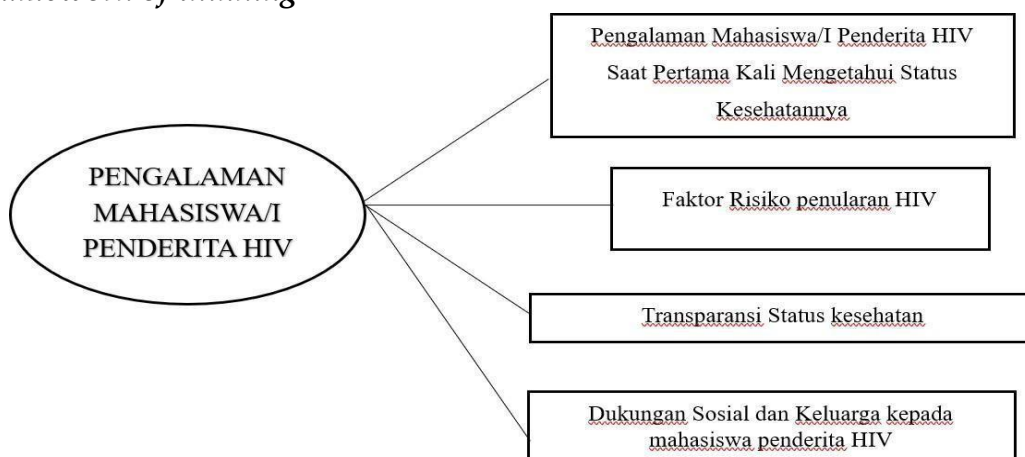


Figure 1. Thinking Framework

## **METHODOLOGY**

This research uses a qualitative research type of phenomenological design. According to Moleong & Surjaman in (Fiantika, Wasil M, Jumiyati,

Honesti, Wahyuni, Jonata, 2022) qualitative research is research that has the aim of knowing the phenomenon of the research subject, for example behavior, perception, motivation, action, etc. using descriptives in the form of sentences and language. According to Creswell In (Ekonomi & Ratulangi, 2022) phenomenology is an approach to research in which the researcher identifies human experiences regarding a particular phenomenon, so from this process the researcher describes symptoms originating from the subject's experiences (Kuswarno, 2007).

This study had seven informants, four of whom were key informants (students with HIV), one educational staff, one family of students with HIV and one peer. In this research, the sampling method used was engineering *Purposive Sampling*. The purposive sample is intended to find out problems directly from informants involved in the social situation that will be studied (Faridi et al., 2021).

Primary data in this research was obtained directly from informants by conducting joint interviews with informants, observing and documenting the experiences of students suffering from HIV in facing social and family stigma within the Swadiri Institute environment. Secondary data consists of literature, personal documents and references, both published and unpublished.

Research regarding the experiences of students with HIV in facing social and family stigma uses a qualitative approach with data collection techniques in the form of in-depth interviews, observation and documentation (Tanzeh, 2018). Semi-structured interviews are the main method for exploring informants' experiences as a whole, supported by field notes and audio recordings. Observations are used to record nonverbal behavior, and documentation in the form of photos supports the validity of the data.

The data analysis process is carried out in three steps, namely data reduction, data presentation, and drawing conclusions Miles & Huberman in (Sugiyono, 2016) . The entire analysis process aims to find the deep meaning of the experiences of HIV sufferers in facing stigma.

The validity of the data is maintained through credibility testing with source triangulation, involving students, families, peers and educational staff (Sugiyono, 2016). The dependability test is carried out through a thorough audit of the research process with the supervisor. All of these steps ensure that the data is valid, reliable, and able to describe the reality of the experiences of students with HIV in facing social stigma in a scientific and comprehensive manner.

## **RESULTS AND DISCUSSION**

The following are the informant criteria in this research:

Table 1. Informant Criteria

Code	Initials	Age	Type	Information
Informant	Informant	(Year)	Sex	
I1	FN	18	Man	Student HIV sufferers
I2	YY	19	Man	Student HIV sufferers
I3	LS	18	Man	Student HIV sufferers
I4	PK	19	Man	Student HIV sufferers
I5	MM	35	Man	Family
I6	RR	31	Woman	Energy Education
I7	A.M.C	22	Man	Friends of the same age

Source: Primary Data, 2025

### ***Experiences of Students Suffering from HIV When They First Learned about Their Health Status***

The age of the informants in this study ranged between 18 and 19 years, which is in line with the findings of research conducted by (Naully & Romlah, 2018) that adolescents aged 18 to 19 years are included in the age group that is vulnerable to HIV infection, this can occur due to risky sexual behavior, lack of parental supervision, and limited access to information and health services. The experience of students suffering from HIV when they first found out about their health status began with various reactions both through actions and feelings. The emotional reactions expressed by informants were feelings of fear, shame, disappointment, sadness and even fear of death.

The reactions of HIV sufferers when they are first diagnosed positively are confusion, depression, shock, anxiety, and denial about the diagnosis (Maulidiah Junnatul Azizah Heru et al., 2024). After students find out about their health status, the actions taken by students also vary, some follow what the doctor or nurse recommends, but there are also those who choose to consume alcoholic drinks and not go to college in the first week after they find out about their condition.

### ***Risk Factors for HIV Transmission***

The main risk factor for HIV transmission revealed by informants was unsafe sexual behavior, especially after consuming alcohol. Alcohol plays a role in reducing self-control, which makes individuals more susceptible to having unprotected sexual relations. This is in accordance with research showing that alcohol consumption can increase the risk of risky sexual behavior. A study

analyzing data from the 2017 Indonesian Demographic and Health Survey (SDKI) on Adolescent Reproductive Health found that male adolescents with a history of alcohol consumption were 7.84 times more likely to be involved in premarital sexual relations compared to those who did not consume alcohol (Hasanah, Winny Kirana, 2022).

In addition, several informants stated that students had sexual intercourse for the first time after a period that was vulnerable to risky behavior, especially if it was not balanced with sufficient understanding of reproductive health and HIV prevention (Aima & Erwandi, 2024). Other factors that can contribute are the lack of comprehensive sexual education, peer influence, and social norms that may not provide enough protection for teenagers in making healthy decisions regarding sexual activity (Hasanah, Winny Kirana, 2022).

### *Transparency of Health Status*

All informants in this study revealed that the student did not tell his classmates about his condition, because he was embarrassed and afraid of being ostracized. This is in line with research conducted by (Rajab et al., 2018) which was conducted in the city of Kendari which showed that some HIV sufferers chose to keep their illness a secret from other people so that they could interact with the people around them as usual.

Based on the interview results, it is also known that the key informant in this study chose to keep his health status a secret from family members who were not close to the student, including mothers or even siblings. HIV sufferers often consider various factors when choosing to reveal their status to their families, so there is some information that they think is worth knowing or hiding from their families (Dhaniswar & Santosa, 2021).

### *Campus, Peer and Family Support for Students Suffering from HIV*

Being a student with HIV is not easy, but with the right coping strategies and support from campus, peers and family, students can undergo the treatment process well without feeling afraid of discrimination (Situmorang & Yona, 2023).

Finding out about HIV disease and then providing education to family members is one of the coping strategies used by informants in this study. By educating themselves and their families about HIV, sufferers can reduce stigma and increase social support, which in turn can improve the mental health and quality of life of HIV sufferers (Priharwanti & Raharjo, 2018). Apart from that, positive support from campus, peers and family really helps students with HIV in the treatment process and increases the self-esteem of HIV sufferers themselves. The forms of support from the campus conveyed by Miss RR as Deputy Chancellor II at the Swadiri Institute are as follows:

*"From the campus itself, as a form of support, we still allow these students to actively participate in lectures, because don't let them feel or think that because they are already HIV positive, it's the end of everything, so even education they can't participate, don't*

*let students think like that, because HIV can still be overcome by increasing their body's immunity, so that they can still study well and the campus also provides posters for HIV like that, how to overcome it, how to transmission, and also how to treat sufferers so that they don't feel intimidated and also from the campus personally conveyed to the student to continue to take care of himself like that so that he is not careless in his life because these students are still young, yes, the turmoil of their love, attraction to the opposite sex is definitely still very, very strong, so we advised them to be able to protect their lives so that they have sexual relations carelessly, especially with campus friends, that's what we have emphasized to protect life and other people. Then, we also carry out health checks, every time we accept new students, when PKKMB is there, we invite the community health center to be able to carry out health checks.."*

a form of support from the campus conveyed by AMK as  
Peers of students suffering from HIV at the Swadiri Institute are as follows:

*"I said this is not the end of everything, because there are still many ways you can take care of your condition, yes, there are still many people who care about you."*

The form of support from the campus conveyed by DM as the family of one of the students suffering from HIV is as follows:

*"As I said earlier, maybe this is God's way of reprimanding you, that's why I, as a brother, just ask him to pray and remind him not to act outlandishly or take medication regularly."*

## **CONCLUSIONS AND RECOMMENDATION**

This study reveals that the initial reactions of students upon learning of their HIV status are predominantly characterized by fear, shame, and even depression. This finding highlights that an HIV diagnosis affects not only physical health but also significantly impacts the psychological well-being of those affected. HIV transmission among students is largely attributed to unsafe sexual behavior, particularly after alcohol consumption, combined with a low level of understanding regarding reproductive health and the prevention of sexually transmitted infections. These factors emphasize the urgent need for early education and awareness within educational environments.

Nevertheless, the study also shows that support from family, campus communities, and peers plays a crucial role in helping students accept their condition, adhere to regular treatment, and cope with the social stigma associated with HIV. This social support has proven effective in fostering hope and treatment compliance, ultimately leading to improved quality of life.

Therefore, it is essential for educational institutions to develop and implement comprehensive, ongoing educational programs on HIV/AIDS and reproductive health. These programs should not only aim to increase knowledge but also encourage healthier and more responsible behavior. Active involvement of family members and peers in the recovery and treatment process is strongly recommended to cultivate a supportive and inclusive environment.

In addition, a continuous and accessible counseling approach is critical to

safeguarding the mental health of students living with HIV. These services should be professionally managed and readily available, allowing students to navigate psychological challenges and societal stigma more effectively. With holistic educational, emotional, and medical support, students living with HIV can be empowered to lead healthier, more productive, and meaningful academic and social lives.

### FURTHER STUDY

This study has several limitations that should be considered for future research development. These limitations include a limited number of participants and a narrow geographical scope, which restrict the generalizability of the findings. Additionally, the research employed a cross-sectional approach, which does not capture the ongoing psychological, social, and treatment adherence dynamics over time. The study also relied heavily on the subjective perspectives of participants and did not fully account for the diversity of students' cultural and socio-economic backgrounds.

Therefore, it is recommended that future research adopt a more comprehensive and in-depth approach. Subsequent studies should also implement a longitudinal approach to examine changes in psychological and social dynamics, as well as treatment adherence among students living with HIV (PLWHA) over time. This is essential to understand how social stigma affects their lives in the long term and how environmental support can impact the quality of life of these students.

In addition, future research could expand the study's location and increase the number of participants by involving students from various regions and higher education institutions, in order to reveal variations in experience based on differences in cultural and socio-economic backgrounds.

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