

PERCEIVED SOCIAL NORM AND FEAR OF STIGMA AMONG YOUNG PEOPLE LIVING WITH HIV IN PALEMBANG

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ABSTRACT

Human immunodeficiency virus (HIV) is a disease that is growing and becoming a global health problem. The purpose of this study was to determine the influence of perceived social norm on fear of stigma among adolescents with HIV in Palembang City. This research used a case study research design. The research sample was 6 key informants who had been infected with HIV as many as 4 MSM adolescents and 2 FSW with an age range of 15-24 years in Palembang. In addition, researchers also explored information through key expert informants, including from the Palembang City Health Office, HIV/AIDS program implementers at health care facilities, and Sriwijaya Plus Foundation. This research used qualitative-descriptive methods and data were analyzed using content analysis techniques. The results showed that people's views of people with HIV are still quite negative. Society perceived people with HIV as disgusting, sinful, dishonorable, terminally ill, and infected by virtue of their karma. This view has resulted in stigma, misunderstanding, rejection and discrimination. As a result, people are afraid that their HIV status will be known to family loved ones, and the community. Therefore, social support, especially from family and close people, is needed to support the survival of people living with HIV. In addition, the role of health workers in educating the public about HIV is needed to eliminate poor stereotypes and behaviors of the community towards people living with HIV.

Keywords : Perceived Social Norm, Fear Of Stigma, HIV

INTRODUCTION

Human immunodeficiency virus (HIV) is a disease that is on the rise and is a global health problem. Based on data from World Health Organization (WHO) at the end of 2021, there were 1.5 million people infected HIV as 650.000 people die because HIV and an estimated were around 38.4 million people living with HIV worldwide. HIV occurs due to HPV (Human Papilloma Virus) infecting and damaging the structure of white blood cells, resulting in a decrease in the human immune system¹.

In Indonesia, HIV incidence has been increasing year by year. In 2022, the incidence of HIV has reached 10.525 cases from 941.973 people tested for HIV². The latest data from the Ministry of Health shows that HIV cases in Indonesia are starting to be dominated by young people, accounting for about 51% of cases. According to Indonesian Pediatric Association, therefore, 1.188 HIV-positive children in Indonesia by age group 15-19 years most vulnerable to HIV/AIDS infection in 2022. Furthermore, the Central Statistic Agency of South Sumatra reported 639 cases of HIV in 2022, with Palembang having the highest number of cases, totaling 353. This information highlights the concerning fact that HIV not only affects adults, but also children and adolescents.

Adolescence is a period of physical, psychological, and intellectual development and growth. While this development does not always result in positive outcomes, it also exposes adolescents to negative influences and may lead to promiscuity due to their high curiosity in various ways³. The occurrence of promiscuity in adolescents may result from several factors including inadequate parental supervision, low self-efficacy, and lack of adolescent awareness, disharmonious family condition, economic conditions, or adverse living environment. Moreover, adolescents may lack maturity, leading to wrong decisions and unawareness of the consequences of their actions⁴.

Behaviors or attitudes that mistreat and underestimate people with HIV are associated with high HIV incidence⁵. This creates problems of human rights violations for people living with HIV and their families⁶. As a result, people living with HIV often feel insecure because they are seen as having infectious diseases.

As a matter of fact, the behavior shown by the community is influenced by the religion that the local community has adopted. Pregnancies outside of wedlock and engaging in sexual activity with multiple partners within some religious doctrines are deemed as sins. Moreover, there exists an assumption that people living with HIV are the consequence of transgressions of norms and karma⁷. This stereotype involves judging individuals who

are not accepted within social circles. Prior research indicates that a majority of Indonesian people adhere to collectivism, which encompasses ideologies, norms, and sociocultural values that align closely with societal attitudes and behaviors⁸.

Societal attitudes contribute to discrimination against those with HIV causing them to fear disclosing their status. This fear can lead to negative feelings of helplessness, inadequacy, failure, unpopularity, and a loss of morale. Consequently, HIV sufferers may give up easily and resort to blaming themselves or others⁹.

Noncompliance, refusal of Anti-Retro Virus (ARV) treatment, and suicidal ideation are potential negative outcomes. This study aims to determine the influence of perceived social norm on fear of stigma among adolescents with HIV in Palembang City

RESEARCH METHODS

This study employed a case study research design. The sample consisted of 6 key informants who had been infected with HIV as many as 4 MSM (male sex male) and 2 FSW (female sex workers) with an age range of 15-24 years in Palembang city. The expert key informants in this study

included the Palembang City Health Office, the implementer of HIV/AIDS programs in health care facilities, and the Sriwijaya Plus Foundation as a foundation which provided in-depth information about adolescents with HIV.

Data FOR this study was collected gathered via in-depth interviews with both main informants and expert information, in addition to document-bases observations within the institution. To ensure data validity, researches employed source triangulation, method triangulation, and data triangulation techniques, including the understanding and coding of data as well as drawing conclusions. Furthermore, content analysis techniques were used to analyze data.

RESULT

This research data was collected by conducting in-depth interviews with all informants in order to gather information. The table below provides an overview of the characteristics of the juvenile obtained through in-depth interviews with all informants obtained:

Table 1. Characteristic of Key Informants with HIV Positive

Informant	Age	Sexual Relationship Status/ Profession	HIV Positive Time Period	Factors which Influence the Sexual Relationship Status/ Informants Profession			
				Economy	Promiscuity	Channeling desire	Utilize Applications
D	24	MSM	1 year 8 months	√	√		√
A	19	MSM	8 months		√		√
B	18	MSM	8 months		√	√	√
M	23	MSM	4 years	√	√		√
N	24	FSW	1 year	√			√
MY	23	FSW	4 months	√	√		√

This study shows that the informant has been HIV positive from less than 1 year to 4 years ago. Furthermore, many factors influence and encourage the informant's sexual relationship or employment status; such as, economic, Promiscuity, Channeling desire, and utilize applications to get partners or clients.

".... Economic needs, there are so many demands life.." (M)

"..It can be said because of promiscuity, I want to channel my desires.." (B)

This statement is supported by the views of expert key informants from the City Health Department, Dempo Public Health Center, and the Sriwijaya Plus Foundation who stated that the most dominant factors in adolscents conducting HIV risk behavior are promiscuity, life's

demands, lack of knowledge and awareness if the act they commit are wrong and lack of affection.

"..because they are want to buy a cellphone, want to wear makeup, want to wear nice clothes. It is of course because of life demands so that they become (sorry) commercial sex worker.." (Y)

"..Because they follow their friends so that they are curious about things... their parents also don't really pay attention to social interactions and what their children do.." (R)

Responding to informants who have been infected with HIV, this study observes the community's assessment or views towards HIV sufferers. It can be learned from the following table :

Table 2. Perceived social norms for informants suffering from HIV

Informant	Perceived social norms for informants suffering from HIV								
	Views from Society				Things that are felt from the views and treatment of society				
	Seen as disgusting, sinful, and disgraceful	Seen as bad and hated	Seen as a result of behavior	Receive gossip	Deadly diseases	Sad	Close themselves off	Angry	Not care
D					√	√			
A	√						√		
B				√				√	
M					√				√
N		√	√			√			
MY				√					√

The study shows that the public's assessment or view of HIV sufferers is quite poor. People think that HIV is a deadly disease, sufferers are seen as disgusting and sinful; besides, they are viewed as a disgrace and they are considered infected as a form retribution for their actions.

“..People views HIV as a deadly disease and it is easily transmitted..” (D)

“..People blame that this is the result of your behavior so far..” (N)

According to informants, people in general are still unfamiliar with HIV. It is supported by interviews which had been conducted with key informants who stated that people are still unfamiliar with HIV, which gives rise to stigma and discrimination.

“..View bad at them, too afraid to socialize with HIV sufferer, afraid of getting infected..” (Y)

“..People assumption is that using the toilet can spread, that with a simple kiss it can be transmitted,

mosquito bites are contagious, food used by HIV is contagious. Like always making mistakes so that always rejected..” (S)

Due to people's view, informants feel sad, want to get angry, close themselves off, or even not caring about the public's response.

“..I feel sad, I like to cry, they like to talk about me behind..” (N)

According to key informants at the Dempo Public Health Center and Sukarami Public Health Center, they stated that the public should be able to give the same view as other diseases.

“..I emphasize to the public that HIV is the same as other diseases..” (R)

Through the perspective of social norms for informants who have been infected with HIV, it leads fear of stigma or fear arises from self-perception due to judgment or views of society. These fears are as follows:

Table 3. Fear of Stigma Felt by HIV Sufferers

Informant	Things feared about the HIV status suffered by informants			
	Fear of the Virus Spreading	Fear of parents/friends/neighbors to know	Fear of Death	Worried about future health conditions
D	√			
A		√		
B			√	
M		√		
N				√
MY		√		

Based on table 3, informants feel afraid if their HIV status known by family, friends or neighbors; besides, they afraid that the virus will spread further in the body, afraid that the time of death is near, and worried about their health condition in the future. Even though they have different reasons, all informants are afraid of their HIV status.

“..I'm afraid that my parents will know that I have this disease..” (MY)

“.. I'm afraid of death..” (B)

This informant's statement is supported by responses from expert key informants from Dempo Public Health Center and Pembina Public Health Center who stated that most sufferers are afraid that they will be known to be HIV positive patients.

“..There are PLHIV who don't want to be reprimanded on the street since they are afraid that they will be discriminated later..” (B)

"..Afraid of adding to the parents' anxiety, then embarrassed if it turns out it is because of the XX factors.." (S)

In order to reduce society's negative views or reduce and eliminate these fears, informants regularly take ARV drugs to feel healthy and feel normal like other people. Moreover, other informants stated that they got motivation from seeing HIV sufferers or other peer supporters in good health. The informant also added that joining Sriwijaya Plus and meeting fellow HIV sufferers made him feel less lonely. It is due to the concern of peer supporters so that the informant understand HIV from fellow sufferers.

"..There are peer supporters like seeing that older siblings who are PLWHA are healthy.." (A)

"..By regularly taking the medicine every day.." (B)

Referring to the negative views received by HIV sufferers, expert key informants have a role in overcoming it with the majority providing education to the public regards to HIV disease.

DISCUSSION

The negative attitudes and views of society towards people living with HIV cannot be disconnected from the societal stereotype that associates HIV disease with negativity. This assumption has been ingrained for so long that it is intricately connected with social issues that give rise to stigma in society. Stigma persists due to ignorance about HIV-related matters. Unfair attitudes and perceptions towards people living with HIV are often influenced by a lack of knowledge or information regarding the transmission of the virus¹⁰.

Stigma plays a significant role in society's existing order and norms, leading to discrimination and human rights violations against people living with HIV (PLHIV)¹¹. Discrimination against PLHIV takes various forms, such as negative attitudes, unfair treatment, avoidance, blame, workplace exclusion, verbal or nonverbal abuse, and rejection by their families or social circle, resulting in reluctance to be accepted in groups¹².

Public misconceptions about HIV can lead to discrimination and rejection that causes people living with HIV (PLHIV) to feel fearful if others, including their loved ones, become aware of their status. Additionally, PLHIV may experience anxiety about the potential impact of HIV. This fear is based on community beliefs that HIV infection is a result of deviant behavior and actions that do not align with societal norms⁵.

Thus, the views and behaviors of people have a variety of physical, social, and psychological effects on people living with HIV.

a) Physical impact

The physical impact experienced by people living with HIV includes weight loss, changes in appearance, skin disorders, and fatigue. This results from the burden that must be carried by the affected person. This burden

encompasses the courses of the disease, the development of secondary infections and stress triggered by uncertain healing processes¹³.

The physical impact felt by people with HIV is in the form of weight loss, changes in appearance, skin disorders and fatigue. This is due to the burden that the person has to carry. The burden includes the course of the disease, the emergence of secondary infections, stress due to uncertain healing processes, and anxiety.

b) Social Impact

The social impact of HIV felt by people living with HIV is stigma, discrimination, ostracism and acts of violence against people living with HIV. The social impact that occurs due to the stigma that exists in society. In addition, the social impact that occurs in the form of social problems in the face of negative views and treatment by society, including people around them who have previously tended to be discriminatory, such as not caring, suspicious, viewed negatively, shunned and ostracized⁹.

This is supported by the findings of previous studies that the majority of people closest to the patient do not know the patient's HIV status. People with HIV state that those around them are not worried or sad, are not discriminated against, and are not ostracized by their family or community¹⁴.

c) Psychological Impact

Based on this, individuals suffering from HIV who perceive themselves near death face a psychological impact, leading to the loss of self-confidence, increased anxiety, and changes in self-concept. Furthermore, societal negative views can affect the health of HIV-positive individuals, manifesting in the form of negative self-conception whereby they perceive themselves as weak and likely to give up easily⁹.

As a result, self-concept refers to an individual's entire self-image, which encompasses their perceptions, beliefs, and values. This concept can be divided into two categories: positive self-concept and negative self-concept.

Positive self-concept involves the capacity to accept life's circumstances and remain objective, realistic, and unemotional. Negative self-concept, on the other hand, entails the inconsistent assumptions about oneself. This leads individuals to lack certainty when it comes to their abilities, weaknesses, and values, resulting in self-isolation, suicidal ideation or self-harm, and feelings of worthlessness and hopelessness¹⁵.

In addition, the psychological impact on people living with HIV is highly stressful during development¹⁶.

Research suggests that HIV patients often experience fear of the virus spreading, as well as fear of their friends, colleagues, and parents knowing their status, resulting in rejection. These patients may also experience anxiety about their future and the possibility of death..

Therefore, community-provided social support is crucial for the survival of individuals living with HIV, especially from those closest to them. Social support entails

offering comfort, a sense of self-worth, attention, and assistance. Consequently, individuals living with HIV will feel valued, accepted, and free from discrimination in society with the provision of social support¹⁵.

Social support can also relieve anxiety and stress in people with HIV, which will ultimately have an impact on better survival of sufferers. In this case, the role of health workers is needed to overcome negative views and community behaviors that have been experienced by people with HIV¹⁷. This role involves providing education and disseminating information to community leaders and the wider community in a manner that is accurate and appropriate with regard to HIV¹⁸.

Not only is support from healthcare professionals crucial, but social support from family and loved ones for HIV sufferers is also necessary to suppress the spread of the infection. Previous research suggests that family support has a significant impact on the quality of life of people with HIV¹⁹. In the final analysis, social support is closely linked to the well-being of people living with HIV²⁰.

The presence of social support may impact a patient's ability to cope with their illness. Another aspect of social support for individuals with HIV is their adherence to taking antiretroviral medications (ARVs). Theoretically, familial support may have an impact on an individual's attitude and behavior, particularly those with specific medical conditions¹⁷.

CONCLUSION AND SUGGESTION

The results of the study state that people views HIV sufferers as someone who is disgusting and sinful, a disgrace to the family or environment, has a deadly disease, and they are viewed infected as a result of the actions they take. This assumption gives rise to stigma which ultimately leads to misunderstanding, rejection, and even discrimination against HIV sufferers. It is the reason why HIV sufferers are afraid that their status as HIV patients will be known by their family, those closest to them and the community. Therefore, as a result, sufferers feel sad, afraid, want to be angry with themselves, and even isolate themselves from society. Thus social support is needed from family and those closest to them in order to support the survival of HIV sufferers. In addition, health workers should participate in educating the wider community regarding HIV in order to eliminate public perceptions and bad behavior towards HIV sufferers.

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