Overview of Stigma ODHA

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Overview of Community Stigma and Self-Stigma related to HIV and AIDS

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Abstract: Stigma causes PLWHA to experience obstacles in the treatment and care process because people living with stigmatized health conditions are confined to live in the same society, but are still moved and experience their own stigma. Stigma has two understanding points of view, namely community stigma and self-stigma. The stigma of society towards PLWHA occurs at various levels, starting from the family, community, institutional environment, and the mass media. Self stigma (self stigma) is a crisis from people who are stigmatized to apply the stigma to themselves. The general objective is to provide an overview of various cases of stigma against PLWHA from a community perspective and self-stigma. Analysis of this paper is carried out through literature review by examining written sources such as scientific journals, reference books, literature, encyclopedias, scientific essays, and other reliable sources either in written form or in relevant digital formats without going directly to the field. This paper is expected to provide benefits and input, as well as a consideration for decision makers in order to review and determine various policies related to the handling of stigma against PLWHA

Keywords: PLWHA, Community Stigma, Self Stigma

INTRODUCTION

People with HIV and AIDS (PLWHA) are people who have been infected with the HIV virus so that their immune system has been reduced. They are very susceptible to disease. In addition to their illness, they often face stigma and discrimination from the community so that PLWHA does not dare to reveal that they are HIV positive. Factors that cause stigma in society against PLWHA are the low level of education and public knowledge about HIV and AIDS in addition to the

lack of socialization or counseling about HIV and AIDS, especially the modes of transmission and prevention so that people have the wrong response about PLWHA.

This is in line with the results of a study in 2000 in Achan, et all (2015) which explained several factors that led to the emergence of stigma and discrimination. First, the lack of knowledge about HIV and AIDS. Second, wrong responses about the mode of transmission of HIV. Third, errors in seeking action and treatment. Fourth, there

is an inaccurate pioneering of the epidemic and the assumption that HIV and AIDS cannot be cured. Finally, there are prejudices and excessive fear of sensitive social issues.

Stigma comes from the mind of an individual or society who believes that HIV and AIDS is the law of karma as a result of one's own actions. Society often says that a person will reap the rewards of what he has done. The stigma is reflected in a cynical attitude, feelings of excessive fear, and negative experiences towards PLWHA (Maman, 2009).

According Corrigan and to Kleinlein (2005), stigma has two perspectives, namely societal stigma and self-stigma. Community stigma occurs when the general public agrees with a person's bad stereotypes (eg, mental illness, pecans) and self stigma is a consequence of stigmatized people applying stigma to themselves.

This stigma causes PLWHA to experience barriers in the treatment and care process because people living with stigmatized health conditions often live in the same society, but remain isolated and confined in their own experiences of stigma, suffering various social, physical and mental health consequences (Corrigan & Rao, 2012; Earnshaw & Kalichman, 2013; Rai et al., 2020).

Health-related stigma has negative impact on the lives of people living with a variety of health conditions and undermines public health responses to curb the burden of the disease (Rai et al., 2020). If the problem of stigma against PLWHA continues to be silenced and is not resolved immediately, the stigma will have a direct impact on the process of treatment and care for PLWHA. According to Carr and Gramling (2004) The rejection caused by this stigma affects access to health care, medication adherence, social interactions, and social support. This will be even worse if it is accompanied by negative perceptions among PLWHA themselves about their existence, so that they become resigned and increasingly depressed and lose their self-confidence.

Based on the background of the problem above, the writer tries to describe various cases of stigma against PLWHA from the community's point of view and *self-stigma*). This paper is expected to provide benefits and input, as well as be a consideration for decision makers in the context of reviewing and establishing various policies related to handling stigma against PLWHA.

METHOD

This study is a qualitative that is literature (*library research*) by examining how a reliable source either in written form

or in a digital format that is relevant without direct down spaciousness (Subagyo, 1991: Hadi, 1995). The literature study here is a literature study without empirical testing (Muhadjir, 1998). According to Sugiyono (2012) literature study is a theoretical study, references and other scientific literature related to culture, values and norms that develop in social situations.

The data analysis technique used is content analysis method (content analysis). This analysis is used to obtain valid information and can be re-examined based on the context (Kripendoff, 1993; Sabarguna, 2005). In this analysis, the process of selecting, comparing, and combining various relevant meanings related to HIV and AIDS will be carried out from the point of view of community stigma and self- stigma.

There are two sources of data in this study, namely: 1) primary source is a reference that is used as the main source of research reference. In this study, the primary source used was Deacon and Stephney's 2007 article entitled *HIV/AIDS*, stigma and children: A literature review.

2) Secondary sources are supporting and complementary references to primary sources. In this study, secondary sources were journals and news articles related to HIV and AIDS.

The methods and steps used to collect data in this study were the

selection of topics related to stigma associated with PLWHA, information exploration, determining focus, collecting data sources, preparing data presentation, and preparing reports. The data presented is data in the form of words that require processing to be concise and systematic (Muhadjir, 1998). While the writing instrument in this article is a *checklist for the* classification of writing materials, writing schemes/maps and the format of writing notes.

RESULT AND DISCUSSION

HIV and AIDS first occurred among homosexual/gay men, and drug abusers (CDC, 1981). Based on this case, the community considers that HIV is a result of people who behave in violation of religious norms and teachings so that they are considered worthy of being infected with HIV. This ultimately creates a stigma that leads to discriminatory behavior for everyone who is HIV positive (Putra, et al, 2019). Stigma against PLWHA has a major impact on HIV and AIDS prevention and control programs, including the quality of life of PLWHA (Utami, 2018; Rai, et al, 2020). At-risk populations will be afraid to take an HIV test because if the results are revealed to be reactive it will cause them to be ostracized. People living with HIV are afraid to reveal their HIV status and decide to postpone seeking treatment if they are

sick, which will have an impact on their declining health and uncontrollable HIV transmission. The impact of stigma and discrimination on pregnant PLWHA women will be greater when they do not want to seek treatment to prevent transmission to their babies.

There is a negative impact from the stigma obtained by PLWHA, so efforts are needed from various parties to find solutions so that the problem of stigma against PLWHA does not increase. This paper is very important to carry out because the increase in cases of stigma continues to increase at every stage so that it hinders the achievement of the SDG's by 2030. This can be seen from the findings of Raka (2020) in his book entitled disinformation which is discrimination against HIV problems in Indonesia, explaining that throughout 2016 -2019 Community Legal Aid Institute (LBHM) found 644 cases of stigma discrimination, with details of 387 cases in 2016-2017, 170 cases in 2018. and 87 cases in 2019. The update of this study is to look at the stigma obtained by PLWHA in Indonesia is based on the opinion of Corrigan and Kleinlein (2005) regarding two angles of stigma. Therefore, the study in this paper begins with a discussion of the general definition of stigma and continues with the definition of stigma related to HIV and AIDS. After that, the

discussion focused on discussions related to two points of stigma, namely self-stigma and community stigma. The discussion in this paper discusses the image of the stigma obtained by PLWHA in Indonesia based on self-stigma and community stigma.

Definition of stigma

In Greek, stigma is a 'tattoo', which is a sign made with a hot iron and pinned on the body to show that the person in question has committed an immoral act, thus giving the impression that the person has carried out behavior that is against the rules of their custom (Pharris et al., 2011; Tristanto et al., 2020).

Literally stigma refers to some form of mark or stain, as stated by Osberne in Page (1984). "Stigma dates back to the Greek word for 'tattoo-mark', a brand made with a hot iron and impressed on people to show that they were dedicated to the services of the temple or, on the opposite spectrum of behavior, that they were criminals or runaway slaves". Another opinion regarding stigma was expressed by RW English in Page (1984) "In the final analysis, stigma might best be considered to be the negative perceptions and behaviors of so-called normal people to all individuals who are different from themselves".

In a more general sociological view, according to Kando in Page (1984) explains that stigma can refer to a dubious and inappropriate nature. Goffman (1963) argues that stigma is an attribute, behavior, or social reputation that discredits in a certain way. Stigma comes from the mind of an individual or society that believes something is the result of immoral behavior that is unacceptable to society.

The United Nations Program on HIV and AIDS (UNAIDS), an HIV and AIDS program with the United Nations, defines stigma related to HIV as a negative characteristic given to a person that causes unfair and unfair actions against that person based on their HIV status (Tristanto, et al. al., 2020a). While AIDSrelated stigma is all suspicion, humiliation and discrimination directed at PLWHA and individuals, groups or communities associated with the PLWHA (Eka, et al., 2012). Stigma in relation to HIV and AIDS is defined as a bad label related to the problem of HIV and AIDS. This bad stamp comes from one person, then spreads to other people in society so that it becomes a social stigma (Tristanto et al., 2020). Stigma and discrimination related to HIV and AIDS take various forms and are manifested at various levels—country, community and individual-and also in various contexts (Latifa & Purwaningsih, 2011).

UNAIDS in Tristanto et al (2020) divides HIV and AIDS stigma into three categories, namely instrumental stigma, symbolic stigma, and decency stigma. Instrumental Stigma is a stigma related to fear of things related to deadly and infectious diseases. The point is that stigma arises as a result of the causes and consequences of HIV and AIDS, for example society stigmatizes PLWHA as people who are about to die.

Symbolic stigma is the stigma associated with the use of HIV and AIDS to express attitudes towards certain social groups or lifestyles that are considered to be related to the disease, such as someone becoming PLWHA because of the association in the past that likes to change partners. While the stigma of decency is a social punishment for people who are related to HIV and AIDS issues or people who are HIV positive, such as PLWHA, are dismissed from the workplace with no respect.

Similar to categories, stigma also has its own dimensions. The dimensions of the stigma of HIV and AIDS are the same as those of stigma in general. Jones in Link et al, (2013) identifies six dimensions of stigma, namely: 1) Concealability, namely the extent to which a condition can be hidden or invisible to others. Examples: how well PLWHA can hide their identity in front of their families and

communities; 2) Course, explaining how condition of people who stigmatized changes from time time. Examples: the ability of PLWHA to survive; 3) Strains, explain interpersonal relationships become tense. Example: The relationship between PLWHA and the environment around PLWHA by knowing the status of PLWHA. 4) Aesthetic Qualities, explaining how a person's appearance is strongly influenced by stigma conditions. Example: An PLWHA is able to appear normal in the midst of the stigma he experiences; 5) Cause, explains whether a person experiences stigmatization because it is congenital or after adulthood. For example: differences in attitudes towards self-acceptance because HIV can come from parents, with attitudes of PLWHA who are infected with HIV because of their actions as adults; 6) Peril. explaining the possibility of harm to others related to stigmatized conditions. Example: the influence of PLWHA on their families

Stigma against PLWHA is reflected in a cynical attitude, excessive feelings of fear, and negative experiences towards PLWHA. Many think that people infected with HIV and AIDS deserve punishment for their own actions. They also assume that PLWHA is the person responsible for

the transmission of HIV and AIDS (Maman et al., 2009).

HIV and AIDS stigma

Stigma against PLWHA appears along with the spread of the HIV and AIDS virus itself. UNAIDS (2008) explains that stigma associated with HIV is a negative characteristic that is given to a person, causing unfair and unfair actions against that person based on their HIV status. While AIDS-related stigma is all suspicion, humiliation and discrimination directed at PLWHA and individuals, groups or communities associated with the PLWHA (Eka, et al., 2012).

Zhou (2007) in his writings argues that the stigma of HIV and AIDS is an individual deviation from socially accepted standards of normality, where this includes deviations from morality, promiscuity, and drug abuse. Therefore, people living with HIV are socially constructed as very different people so that they can threaten the general public. From these two opinions, stigma in relation to HIV and AIDS is defined as a bad stamp related to the problem of HIV and AIDS.

Stigma related to HIV and AIDS occurs because of three sources, First: fear, everyone knows HIV and AIDS is an infectious disease for which there is no cure. Second: Moral, HIV and AIDS are often associated with risky sex and drug

abuse, God's curse on the grounds that PLWHA are people who have violated religious norms. Third: ignorance by the mass media and the fear and moral thoughts of readers (Green, 1980).

Stigma related to HIV and AIDS takes various forms and is manifested at various levels-country, community and individual—and also in various contexts (Latifa & Purwaningsih, 2011). Stigma against PLWHA is reflected in a cynical attitude, excessive feelings of fear, and experiences towards negative PLWHA. Many people think that people infected with HIV and AIDS deserve punishment for their own actions. They also assume that PLWHA is the person responsible for the transmission of HIV and AIDS (Maman, et al, 2009).

This is what causes people with HIV infection to receive unfair treatment, discrimination, and stigma because of their illness. Social isolation, dissemination of HIV status and rejection in various spheres of community activities such as education, the world of work, and health services are forms of stigma that often occur (Carr, et al, 2004; Maman, et al, 2009). The high community and environmental rejection of the presence of people infected with HIV and AIDS causes some PLWHA to live by hiding their status (Foster, et al, 2000; Butt, 2010).

Stigma's Point of View

Community stigma

Community stigma is a feeling that a person or group feels they are superior to others and causes another person or group to be socially excluded which ultimately leads to social inequality (Parker & Aggleton, 2003).

The process of the occurrence of a societal stigma starts from the individual or community labeling certain individuals or for their characteristics groups these differences. From labels. it encourages the emergence of individual or community beliefs about individuals or groups who are different from their own culture. This belief then places the individual or group into a different category from society in general so that there is a separation. In the end, different individuals or groups get different treatment (discrimination) from society (Rizki et al., 2020).

According to Major & O'Brien (2005), the mechanism of stigma is divided into four, namely: 1) the existence of negative treatment and direct discrimination, which means that there are restrictions on access to life and direct discrimination so that it has an impact on social status, psychological well-being and health. physique; 2) stigma becomes a process through the confirmation of expectations or self-fulfilling rophecy. 3) stigma can be a process through the automatic activation of negative stereotypes in a group; 4) there is a threat to the identity of the individual.

Stigma in oneself (self-stigma).

Stigma yourself (self-stigma) is a consequence of people stigmatized stigma themselves (Tristanto, apply 2020b). According to Corrigant and Rao (2012) self-stigma is also often equated with negative self-acceptance, which is someone's recognition that the public has bad prejudice and will stigmatize them. In particular, they will feel devaluation or self-depreciation and discrimination that causes a decrease in self-esteem and individual beliefs about their abilities to carry out tasks or actions needed to achieve certain results or better known as self-efficacy. Stigma that judges negatively against oneself is one of the factors that can perpetuate discrimination. Because, with reduced self-confidence acceptance of oneself through a way of thinking, it will create pessimism or failure towards the individual himself, such as a feeling of not worthy of the opportunity or opportunity that exists so that it weakens the effort on that opportunity or opportunity.

In the concept of stigma on oneself there is also the concept of " *The Why Try Effect*" or the "why try" effect. This effect

is a consequence of self-stigma where selfstigma interferes with the achievement of one's life goals. Self-stigma serves as a barrier to achieving life goals. However, self-esteem and self-efficacy can actually reduce the harmful effects of stigma on self (Corrigan & Rao, 2012).

The relationship between community stigma and self stigma (self stigma)

Community stigma is closely related to self-stigma because self-stigma will be formed when someone believes that the stigma that society has given them is the truth. In general, people with this condition are aware of the phenomena that exist in society about their condition. This stage is called the stage of Awareness (Awareness). This person then agrees that negative stereotypes about them in public is true, this stage is called the stage Agreement (Agreement). Furthermore, the person agrees that this stereotype applies to himself or is called the Application stage (Apply). This causes significant loss, decreased self- esteem and self-efficacy, so that this stage becomes the final stage of self-stigma called Loss (Harm) (Corrigan & Rao, 2012).

Society's Stigma related to HIV and AIDS

Various writings report that many PLWHA receive negative stigma from the community, especially from those closest to PLWHA. This stigma is reflected in the perception of negative treatment in the form of avoidance, humiliation, rejection in social interactions, and job loss (Li, et al., 2012). Negative treatment arises from the fear of being infected, where a person feels uncomfortable when in direct contact with PLWHA or with objects used by PLWHA (Ardani & Handayani, 2017).

Social isolation, dissemination of HIV status and rejection in various spheres of community activities are forms of community stigma against PLWHA in society (Carr & Gramling, 2004). The stigma is influenced by several assumptions, such as diseases that cannot be prevented or controlled, diseases caused by "immoral people", and diseases that are easily transmitted to others. Therefore, people living with HIV are often labeled as others. It is another race, another human, or another group (Ardani & Handayani, 2017; Deacon & Stephney, 2007).

In addition, PLWHA often face wrong spontaneous reactions from the community, including some from the medical community themselves, such as distancing themselves from PLWHA, trying not to touch PLWHA, using disinfectants and even burning mattresses or used clothes of PLWHA (Nasronudin, 2014).

Community stigma against PLWHA occurs at various levels, ranging

from family, community, institutional environment (education and work), and mass media (Achan & Agung, 2015; Tristanto et al., 2020). Stigma that occurs in the family environment includes the exclusion or disposal of PLWHA to remote places outside the city, exclusion of PLWHA from the family inheritance list, separation of toiletries and eating utensils (Eka et al., 2012). One example of the case occurred in a man living with HIV in Rembang who was rejected by his family (Syaefudin, 2017).

Stigma in the community includes refusing the existence of PLWHA, so they are not allowed to live in the community. As reported by merdeka.com on October 22, 2018, with the title residents, five orphans living with HIV are threatened with expulsion from Samosir. In the news, it was explained that five orphaned children with HIV were given an ultimatum by residents to leave Samosir no later than October 23, 2018 because residents were afraid of transmission (Muhardiansyah, 2018).

Stigma in institutional environments such as education is the existence of schools that openly refuse PLWHA to enter educational institutions on the grounds that they will infect other students or students around them (Achan & Agung, 2015). One of the most striking cases of stigma in educational institutions

is that 14 children with HIV and AIDS (ADHA) in Solo experienced rejection from their parents (Mabruroh, 2019). In addition, there are also schools that openly refuse PLWHA to enter educational institutions on the grounds that they will infect other students or students around them (Achan & Agung, 2015).

While the stigma in the institutional environment in the workplace is that PLWHA is removed from the workplace unilaterally and disrespectfully for no apparent reason when the company finds worker the status of the concerned. This is as told by Ayu Oktarian on beritabaik.id with the title story of a woman living with HIV, being fired and being slapped by a child (Budiana, 2018). In addition, the form of stigma in the institutional environment in the workplace is to include discriminatory conditions, namely prospective workers must be free from HIV and AIDS, as was done by Bank Papua which requires prospective employees to be free of HIV as evidenced by a certificate from the hospital (Sobolim, 2007).

The mass media is the last level of public stigma against PLWHA. Although the mass media is not a group of people or an association which is a requirement of a society, in sociology the mass media can be classified as part of society in the category of community socialization media

(Tristanto et al., 2020b). This is because the mass media can carry out wider socialization activities.

This is because the mass media is too much in making news headlines and the news that is conveyed is only half-hearted, such as news about "HIV and AIDS are diseases that have no cure" or "HIV and AIDS are deadly diseases". If PLWHA reads or hears the news, they will despair.

In addition, a form of stigma that comes from the mass media is the disclosure of the HIV status of an PLWHA without the person's permission. This information leak is carried out by the media to the public by exposing their health status, which ultimately creates stigma and protection for victims whose status is disclosed (Raka, 2020). A person's HIV status is a sensitive private matter so it should not be disclosed by anyone for any reason without the consent of the person concerned.

Stigma in Self (*Self Stigma*) related to HIV and AIDS.

HIV and AIDS still has a frightening image among the public, especially PLWHA themselves, apart from the mode of transmission, AIDS is considered a death sentence. People who are first diagnosed with HIV and AIDS often feel depressed, afraid, depressed and

hopeless. This causes **PLWHA** stigmatize and discriminate themselves. This incident is still often found in PLWHA in the city of Bandung, especially in PLWHA who are younger, around 15-24 years old (Eka et al., 2012). When first diagnosed with HIV, many PLWHA feel anxious that they will no longer be accepted in their family, environment and community and are afraid to face the future so that PLWHA no longer want to socialize, do not want to continue their education or tend to commit suicide. People living with HIV who are older are less likely to experience stigma because they have reached a level of stability and self-confidence.

CONCLUSION

This stigma reflects a deep social class bias. The disease is often associated with behavior and becomes a justification social injustice. Stigma against PLWHA occurs in almost all levels of society, namely family, peers, school or environment and the work mass media. Factors that cause stigma in society against PLWHA are the low level of education and public knowledge about HIV and AIDS in addition to the lack of socialization or counseling about HIV and AIDS, especially the modes transmission and prevention, so that people assumptions have wrong about

PLWHA. Community stigma is closely related to self-stigma because self-stigma will be formed when someone believes that the stigma that society has given them is the truth.

If the problem of community stigma against PLWHA is silenced and not resolved immediately, this stigma will continue to grow around the community. PLWHA are excluded and rejected everywhere so that it has a direct impact on the treatment and care for PLWHA. This is because PLWHA feel afraid, embarrassed, ignored and get discriminatory behavior and there is no positive support.

This will be even worse if there is a negative perception among PLWHA themselves about their existence as well as other people, so that they become resigned and increasingly depressed and lose their self-confidence. In addition, PLWHA also experience heavy social and psychological burden so that they do not have the spirit to live. Feelings of psychological pressure on PLWHA will reduce the PLWHA's immune system which has decreased due to the attack of the HIV virus. If the immune system of PLWHA decreases, it will result in opportunistic infections that easily enter the body of PLWHA so that PLWHA is increasingly unable to function socially properly.

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