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Stigma experience by people living with HIV/AIDS in Jakarta

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Abstract

Stigma and discrimination against people living with HIV/AIDS are still given by the community and make them become unopen and feel ashamed if they must go to health services to get treatment, especially during the COVID-19 pandemic. During the pandemic, there are restrictions on visits, examinations and screening of patients entering health services influence stigma and discrimination against PLHA, namely PLHA with decreased immunity. They become confused, afraid, worried, and anxious to face the current situation. As a result, they are reluctant to access health services for fear of being exposed. Purpose: This study aimed to identify the factors influencing the stigma and discrimination experienced by PLHA. Methods: This study used a descriptive quantitative method with a cross-sectional approach. Data were collected using the purposive sampling technique and 149 respondents were obtained from October 2021 to January 2022. The data analysis technique used in this study was multivariate analysis with Logistic Regression Test. This study has passed the ethics code No. 069/KEPPKSTIKSC/VIII/2021. Results: The results of this study show that there is a significant relationship between social support and stigma (p-value 0.000). Furthermore, variables that do not have a significant relationship with stigma are gender (p-value 0.377), age (p-value 0.317), educational background (p-value 0.634), employment (p-value 0.062), marital status (p-value 0.239) and length of infection (p-value 0.940). In the multivariate analysis, it is found that the contribution of the independent variables is 18.1%. Conclusion: This study can provide input for health workers to improve education and encourage them to become friends who provide social support to PLHA, especially regarding the stigma that occurs.

Keywords: Stigma; People Living With HIV/AIDS; Social Support; Community

1. Introduction

HIV/AIDS is a major global public health issue and is one of the goals of the Sustainable Development Goals (SDGs). The HIV virus can enter the human body through sexual intercourse, the use of unsterilized needles and transmission from mother to child (1). According to WHO (World Health Organization) in 2017, it was reported that there were 36.9 million people living with HIV positive and of which, 2.1 million were children (<15 years). It was estimated that 1.8 million people worldwide were newly infected with HIV in 2016—about 5,000 new infections per day. This figure included 160,000 children (<15 years). Around 70% of people living with HIV globally knew their HIV status in 2016, while the remaining 30% (over 11 million people) still need access to HIV testing services (1).

Based on the report on the development of HIV/AIDS and Sexually Transmitted Infections (STI), the number of people living with HIV in Indonesia as of May 2020 was 394,769 people, an increase of 67,196 people from December 2019. Meanwhile, people with HIV who started ART in May 2020 were 202,919 people and people with HIV who were on ART were 134,032 people (2). Every three months there are approximately 15,000 new HIV positive and AIDS cases so every year there are around 40,000 – 50,000 new cases. The government has carried out various programs related to the prevention of HIV/AIDS transmission to achieve the goals of zero new infections, zero people dying from HIV/AIDS and

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zero stigma and discrimination. One of the obstacles in controlling HIV/AIDS is the stigma and discrimination against people living with HIV/AIDS (PLHA). Stigma is a prejudice that arises in the community against a person or group who is considered different from most people or has a disease that is uncommon.

The stigma that arises will result in PLHA being exiled from the community so that treatment will be hindered. The stigma will also result in a decrease in the quality of life of PLHA such as, refusing HIV testing and isolating themselves. Stigma and discrimination are not given by ordinary people who do not have sufficient knowledge about HIV/AIDS, but also by health workers (3). This HIV/AIDS condition is exacerbated by the COVID-19 Pandemic. During the COVID-19 pandemic, health measures taken in response to the pandemic will have far-reaching consequences for HIV disease, due to poverty, decreased food security and reduced economic growth. Many low- and middle-income countries have high burdens of HIV disease, and millions of people depend on large-scale programs for control and treatment in the next 2–4 years. During this highly transformative period, human interactions have been forcibly altered, either through implemented social distancing or lockdowns, to limit the spread of the virus. Reducing the movement, the duration and frequency of contact between people, imposes artificial contact barriers that can lead to friction and strife. Health care systems, often under stress, are unprepared and faced with life-and-death decisions, rekindling, or amplifying sensitive social issues, including stigmatization, discrimination, racism, injustice, and inequality, as the results of health inequalities.

Margareth Chan (the 7th WHO Director-General) states that HIV and AIDS are conditions full of stigma. During a pandemic, the state must remain committed to reducing HIV transmission and preventing AIDS (PPH Atmajaya). This is also reinforced by the conditions that occur in several foundations, namely Muvita Sari (PKBI DKI Jakarta) stating that several situations faced are that HIV testing services must be limited, temporarily eliminating mobile tests, and limiting the number of clients. According to IAC in 2020, the COVID-19 pandemic could reduce the availability of logistics such as condoms, ARVs and sterile injections which causes PLHA to become confused, afraid, worried, and anxious to face the current situation. As a result, they are reluctant to access health services for fear of being exposed.

This will increase the number of people living with HIV and AIDS, while the issue of stigma and discrimination against PLHA and key populations continues and hinders HIV/AIDS prevention programs. Approximately 50% of men and women experience stigma and discrimination related to their HIV status in 35% of countries in the world. As a result of stigma and discrimination, people living with HIV tend to be ostracized by their family, friends, and the wider community. On the other hand, they also experience discrimination against their rights in health care, education, and others. The stigma index of PLHA indicates that 1 out of 8 PLHA does not receive health services because of stigma and discrimination.

(4) stated that many PLHA experience depression due to a lack of social support from the work environment. The impact of stigma and discrimination experienced by PLHA is in the form of ostracism and termination of employment, causing PLHA to choose to work as entrepreneurs. In the study, it was also stated that the stigma felt by PLHA was mostly because they felt guilty about being infected with HIV/AIDS. In addition, they also felt worried about the judgment of others because this is related to deviant sexual behavior.

This is confirmed by (5) that the distribution of the level of stigma among respondents is that 52.7% of the respondents experienced high stigma. High stigma on respondents can be influenced due to a lack of information sources. This is supported by observations during questionnaire distribution. Respondents clearly did not want to fill out the distributed questionnaires unless requested by staff working at the foundation. Respondents also tended to appear introverted to new people who were present among respondents. Furthermore, they were also less comfortable and refused to make eye contact. People with high knowledge do not necessarily have a low stigma and people with low knowledge do not necessarily have a high stigma (6–8).

'C' Room, at X Hospital Jakarta is a place for integrated, holistic services for HIV patients covering aspects of examination, counseling, care, support and treatment. 'C' Room, is serving as many as 3500 patients on ART and screening new patients as many as 180 patients every month. 'C' Room seeks to provide opportunities for PLHA and their families to regain the quality and meaning of life, with the hope that every patient who visits there will feel relief without having to be stigmatized and discriminated against. Based on the above phenomenon, the researchers wanted to analyze what factors influenced the stigma and discrimination experienced by PLHA during the COVID-19 pandemic.

2. Material and methods

This study used a descriptive quantitative method with a cross-sectional approach, namely it was conducted at one time where the collection of the data that were used in this study was done by using questionnaires that were distributed to

patients. The population of this study were all PLHA who visited 'C' Room at X Hospital in Jakarta every day, average there were as many as 2000 PLHA who visited 'C' Room in 1 month. The sample in this study was selected using the purposive sampling technique and 149 respondents were obtained. Respondents who were used as the sample in this study were according to the inclusion criteria, namely respondents aged 17-60 years (productive age) and were willing to take parts in the study. This study was conducted at a private hospital in Jakarta from October 2021 to January 2022 by meeting the research ethics that apply to the study site. This study has passed the ethics code No. 069/KEPPKSTIKSC/VIII/2021. The data collection instrument used was a stigma questionnaire from (Siregar, 2012) with the results of the validity of all questions in the questionnaire are valid (28 questions) and obtain an r value > 0.361; and are reliable (28 questions) and obtain an alpha value > 0.80. The statistical test used was Kendall's tau-b and multivariate analysis used was the Ordinal Logistics Regression Test.

3. Results and discussion

Must be presented in the form of text, tables and illustrations. The contents of the tables should not be all repeated in the text. Instead, a reference to the table number may be given. Long articles may need sub-headings (mentioned on page 1 as Subdivisions) within some sections to clarify their contents.

Table 1 Frequency distribution of respondents living with HIV/AIDS

Variable	n	%
Gender		
Male	140	94.0
Female	9	6.0
Age		
Young Adulthood (18-35 years)	108	72.5
Late Adulthood (36-50 years)	41	27.5
Educational background		
Junior High School	1	0.7
Senior High School	38	25.5
University	110	73.8
Employment		
Employed	14	9,4
Unemployed	135	90,6
Marital status		
Unmarried	127	85,2
Married	15	10,1
Widowed	7	4,7
Length of infection		
≤ 1 year	29	19,5
> 1 year	120	80,5
Social support		
Negative	72	48,3
Positive	77	51,7
Stigma		

High	71	47,7
Low	78	52,3
Total	149	100

Table 1 shows that the majority of respondents are male (94%). Furthermore, the results also show that the majority of respondents are in young adulthood (18-35 years) (72.5%) and have a university educational background (73.8%). The majority of respondents are unemployed (90.6%) and unmarried (85.2%). From the length of HIV infection, the majority of respondents have been infected with HIV for more than 1 year (80.5%). The majority of respondents have positive social support (51.7%) and have/ experience mild stigma (78%).

Table 2 Analysis of variable relationship against stigma

Variable	High stigma		Low stigma		p-value
Gender					
Male	71	95.9%	69	92%	0.377
Female	3	4.1%	6	8%	
Age					
Young Adulthood	58	78.4%	50	66.7%	0.317
Late Adulthood	16	21.6%	25	33.3%	
Educational background					
JHS	0	0	1	1.3%	0.634
SHS	21	28.4%	17	22.7%	
University	53	71.6%	57	76%	
Employment					
Employed	10	13.5%	4	5.3%	0.062
Unemployed	64	86.5%	71	94.7%	
Marital status					
Unmarried	66	89.2%	61	85.2%	0.239
Married	6	8.1%	9	10.1%	
Widowed	2	2.7%	5	4.7%	
Length of infection					
≤ 1 year	16	21.6%	13	17.3%	0.940
> 1 year	58	78.4%	62	82.7%	
Social support					
Negative	46	62.2%	26	34.7%	0.000
Positive	28	37.8%	49	65.3%	

Table 2 shows that based on the results of the Kendall's tau-b statistical test, there is a significant relationship between social support and stigma (p-value 0.000). Furthermore, variables that do not have a significant relationship with stigma are gender (p-value 0.377), age (p-value 0.317), educational background (p-value 0.634), employment (p-value 0.062), marital status (p-value 0.239) and length of infection (p-value 0.940).

The multivariate analysis used in this study was the Ordinal Logistics Regression Test which aimed to analyze factors associated with HIV/AIDS stigma. The ordinal logistic regression test in this study tested the feasibility of model fit, the overall model fit, pseudo-R-square and parameter estimates as well as parallel lines.

The results of the analysis are described as follows:

Table 3 Feasibility test of model fit of factors associated with stigma experienced by PLHA during the Pandemic

Dependent Variable	Test results	Model Fitting Information			
		-2 Likelihood Logs	Chi-Square	df	Sig.
Stigma	Intercept Only	88,968			
	Final	59,208	29,760	9	0.000

Based on feasibility test of model fit in Table 3, it is found in the model fitting information of -2log likelihood that without including the independent variables (intercept only) the value is 88,968, but by including the independent variables into the (final) model, the value decreases to 59,208, meaning that this result supports the theory used and can be confirmed by testing the entire data or fit with existing data. This change in value resulted in a chi-square value of 29.760 and a significant p-value of 0.000.

Table 4 Overall model test

Variable	Group	Chi-Square	df	Sig.
Stigma	Pearson	23,040	30	0.814
	Deviance	30225	30	0.454

Based on the overall model test in Table 4, the results provide information about the model fit with the data. Based on the statistical test, it is concluded that the significance value is > 0.05 so the probability value for the variable is significant. This means that the model can reject the null hypothesis, which means that the stigma model experienced by PLHA is in accordance with the empirical research data.

Table 5 Pseudo-R-square test

Cox and Snell	0.181
Nagelkerke	0.242
McFadden	0.144

The Pseudo-R-Square test based on the Cox and Snell values was carried out to determine the contribution made by the independent variables, namely 0.181, which statistically means that the independent variables can explain the contribution between variables and the dependent variable, namely 18.1%.

Table 6 Parameters estimates test

		Estimates	df	Sig.
Threshold Location	Gender	-1,398	1	0.090
	Age	-0.582	1	0.073
	Educational background	-0.428	1	0.143
	Employment	-1.628	1	0.003
	Marital status	-1.090	1	0.205
	Length of infection	0.384	1	0.249
	Social Support	-1.024	1	0.000

Parameters estimates test show the influence of each independent variable of gender, age, education, marriage, occupation, length of infection and social support partially on the stigma experienced by PLHA. Based on the results of the parameters estimates test in Table 6, the significance level obtained, namely gender = 0.090 with an estimated value of -1.398, age = 0.073 with an estimated value of -0.582, educational background = 0.143 with an estimated value of -0.428, employment = 0.003 with an estimated value of -1.628, marital status = 0.205 with an estimated value of estimated -1.090, length of infection = 0.249 with an estimated value of 0.384 and social support = 0.000 with an estimated value of -1.024. From these results, it can be concluded that partially, a p-value < 0.05 is obtained from employment and social support variables. This means that these two variables have a relationship with the stigma experienced by PLHA during the pandemic.

Stigma against PLHA is a negative assessment given by the community because the HIV disease suffered is considered a result of self-defeating behavior. Stigma against HIV/AIDS arises from the perception of deviations in the behavior of PLHA from social norms in the society (9–11). The stigma given to PLHA often causes a decrease in the spirit of PLHA, which will ultimately have an impact on the quality of life of PLHA. Stigma against HIV/AIDS causes people living with HIV/AIDS to be not treated with respect and dignity. PLHA are insulted, rejected, gossiped about, and excluded from social activities (11). Stigma comes from internal and external of PLHA.

Stigma that arises from within PLHA (internal stigma/ self-stigma) is due to their own fear and is also the result of internalizing external stigma. External stigma is accepted by PLHA in the form of discrimination, intimidation, and exclusion (12). PLHA who feel stigmatized will have less possibility to seek help, delay treatment or choose to end treatment which will ultimately have an impact on HIV/AIDS prevention and control programs and reduce the quality of life of PLHA (12,13). Self-stigma is a mark of shame that someone puts on themselves, judging themselves as someone who is not liked by society. (5) stated that 90.17% of PLHA tried to hide their HIV status from the community and 73.93% of PLHA were worried if the public knew their HIV status. Stigma from the community towards PLHA can still be felt today. This is evident from Manjaw's study (2020) that 5.3% of respondents responded that they do not want to be neighbours with PLHA, cannot live close to or even in the same house with PLHA because they suffer from disgusting diseases. This is also confirmed that 7.5% of respondents refused to live next door to PLHA.

The stigma given will result in acts of discrimination, namely the act of not recognizing or not seeking the fulfilment of basic rights of individuals or groups as human beings with dignity (2). The stigma experienced by PLHA can be caused by several factors. Most of the stigma can occur due to lack of proper information about HIV/AIDS, especially in the mechanism of transmission of HIV/AIDS. This is because PLHA are more likely to close themselves off from their family, friends, and community.

3.1. The Relationship between Sex and Stigma

This study shows that there is no relationship between gender and the stigma experienced by PLHA. Based on the data in Table 2, the majority of respondents of the male gender experienced a high stigma compared to that of the female gender, namely 95.9%. This is because the majority of respondents in this study are males. Also, the high prevalence in males is because they are more prone to same-sex risky sexual behaviour.

3.2. The Relationship between Age and Stigma

Stigma against people living with HIV/AIDS is still a priority in the treatment program in Indonesia. This study is in line with (5) and (14) who state that there is no relationship between age and stigma that occurs in PLHA. The longer PLHA suffers from HIV/AIDS, the more information they can obtain from extension programs, electronic media, internet media and from peers. This shows that PLHA can have sufficient information. Based on the data in Table 2, the majority of respondents who have a high stigma are in young adulthood (18-35 years), namely 78.4%.

3.3. The Relationship between Educational background and Stigma

Table 2 shows that respondents with university educational background who have a high stigma are 71.6% and those who have a low stigma are 76%. This can also be seen in Table 6 which shows that there is no relationship between educational background and stigma with a p-value of 0.142. This proves that people with high educational background do not necessarily have a stigma and those with low educational background also do not necessarily do not have a stigma. People with high knowledge do not necessarily have a low stigma and people with low knowledge do not necessarily have a high stigma.

3.4. The Relationship between Employment and Stigma

Based on Table 1, the majority of respondents (90.6%) are unemployed and in Table 2, data obtained show that respondents who are unemployed and have a high stigma are 86.5% and those who have a low stigma are 94.7%. This is because someone who is unemployed (does not work) does not get the correct and sufficient information related to HIV/AIDS. PLHA who do not work tend to withdraw from their social community. Meanwhile, someone who is employed (works) and still has a high stigma is because the work environment creates a stigma through various regulations, or even fires PLHA.

3.5. The Relationship between Marital status and Stigma

Based on Table 2, it is obtained data that respondents with a high stigma are those who are unmarried (89.2%). Marital status is the state or position of a person in relation to the surrounding community (Nursalam, 2015). Marital status in Indonesia is divided into 3, namely married, unmarried and widowed. PLHA who are married will have higher self-esteem and have adequate coping from their partners so they can develop adaptive coping with stressors. This self-stigma is often equated with negative self-acceptance, where someone admits that the public has a bad opinion of them. This will result in a decrease in self-esteem and self-efficacy (individual beliefs about their abilities to perform tasks or actions needed to achieve certain results).

3.6. The Relationship between Social Support and Stigma

Many people feel weak, angry at themselves—and eventually choose to hide themselves from their family, friends and community after being diagnosed with HIV/AIDS. PLHA feel ashamed to share their condition with family and friends. This will increase anxiety and reduce self-concept that exists in themselves. When people are open about their condition, worry after worry of confidentiality is reduced and they may soon find family members or friends who will support them even after learning about their condition (Corrigan, Roe, Tsang; 2011). Lack of knowledge about HIV/AIDS and how it is transmitted makes people become narrow-minded. Besides, negative labels in PLHA will also develop and at the same time, the community will also provide forms of discrimination such as refusal to care for PLHA, ostracization/alienation, termination of employment.

In Table 2, it is found that people who have negative social support have a high stigma, namely 62.2% and those who have positive social support, have a low stigma, namely 65.3%. In this study, it is also found that social support greatly influences the stigma experienced by PLHA with a p-value of 0.000. Social support can come from family or friends. The family is the smallest unit of society that has a very strong bio-psycho-social-cultural interaction between individuals within them. Dorothea (2020) states that the support needed by PLHA from their families is to be listened to and encouraged. In addition, 72% of PLHA responded that their family had never taken or accompanied them to treatment and had supported them to maintain confidentiality about their illness. (15) strengthens this study, namely that there is a relationship between the attitude of extended families towards PLHA and the stigma given by the community. Family support is very important in increasing the spirit of living of PLHA. Support that is not obtained by PLHA will have an impact on their quality of life.

3.7. Stigma and COVID-19 Pandemic

Stigma experienced by PLHA can happen everywhere. (15) states that PLHA can experience stigma in several places, namely 26.1% stigma in the family, 19.1% stigma in the workplace, 55.8% stigma in health services, 23.3% stigma in the community and 29, 3% stigma in schools. This is further strengthened during the COVID-19 Pandemic where there is a social restriction policy that became a dilemma for efforts to overcome HIV/AIDS. Researchers (16–18) states that during this pandemic, there is less than optimal socialization and education on HIV/AIDS prevention which was usually carried out en masse along with limited digital educational media, postponement/ delay of the implementation of mobile VCT or HIV testing in at-risk populations due to limited resources, and diversion of a control program for the prevention of COVID-19 as well as limited access to antiretroviral therapy and a greater risk of susceptibility of PLHA to be infected with COVID-19.

Hall's study (19) states that eight out of ten PLHA who tested positive for COVID-19 considered their HIV diagnosis to be a bigger impact on their lives than the COVID-19 diagnosis. Respondents who experienced both HIV/AIDS and COVID-19 expressed fear of experiencing multiple discrimination because of HIV/AIDS and COVID-19. During this pandemic, it becomes more difficult for PLHA to receive treatment or grow in the economy. Research from (20) stated that connection between discriminatory views towards HIV/AIDS and stigma is education. Education is one of the most effective ways to limit the spread of HIV. Young people nowadays are more likely to use modern media and have easier access to information through social media. Education is the key to dispelling prevalent myths and assisting those in need to overcome this HIV epidemic.

(21) stated that correlations between stigma and the use of HIV services or the effects of stigma on HIV treatment program is limited. There is also a lack of standardized instruments to measure HIV/AIDS related stigma. PLWH report experiencing barriers to care as feelings of being judged, fear of prejudice and emotional responses ranging from futility to frustration and even anger.

3.8. Implication and Limitations

For People with HIV/AIDS: People with HIV/AIDS can improve their coping skills in overcoming the stigma that exists in their surrounding communities to improve their quality of life.

For Health Workers: The results of this study can provide input for health workers to be able to provide optimal support for PLHA, especially in the form of adequate health services to assist PLHA in achieving a better quality of life without giving stigma or discrimination against PLHA

4. Conclusion

Stigma against PLHA is experienced in all communities, especially during the COVID-19 pandemic, is quite large and PLHA has a burden of vulnerability experienced. The fear and anxiety of PLHA influence not only their physical and mental health but also their social stigmatization. The findings obtained in this study reveal that the most influential factor in the stigma experienced by PLHA is social support from family, friends, and the surrounding communities. Based on the results of the study conducted, it can be concluded that: The factor influencing the stigma and discrimination experienced by PLHA during the COVID-19 pandemic is social support. In the multivariate analysis, it is found that the contribution of the independent variables is 18.1%.

Compliance with ethical standards

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Disclosure of conflict of interest

The authors declare that we have no competing interests.

Statement of ethical approval

All procedures performed in studies were in accordance with the ethical standards at Sint Carolus School of Health code No. 069/KEPPKSTIKSC/VIII/2021.

Statement of informed consent

Informed consent was obtained from all individual participants included in the study.

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