ORIGINAL ARTICLE

Stigma and Anxiety Levels With Adherence on the Treatment Schedule Patient With HIV/AIDS in Indonesia

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ABSTRACT

Introduction: The stigma related with HIV/AIDS poses a psychological challenge to people living with HIV/AIDS. Adherence to the treatment schedule is very important to reduce the impact of HIV/AIDS. Stigmatization is a social problem that affects physical health. As a result, the patients are anxious and react negatively to medication adherence. This study analyzes the stigma, anxiety, and adherence to treatment schedules for HIV/AIDS patients in Surabaya, Indonesia. **Methods:** : The present study used correlational research, involving 97 respondents, chosen by simple random sampling. The instruments of stigma variable used Berger HIV Stigma scale, variable of anxiety used Zung Self-Rating Anxiety Scale (ZSAS), and variable of adherence to treatment schedules used modified Morisky Medication Adherence Scale-8 (MMAS-8) in which all instruments used have been tested for validity with the Cronbach's alpha value > 0.90. Data analysis used the Spearman rho test with the p-value ≤ 0.05. **Results:** The results show that there is a relationship between stigma (*p*-value = 0.012) and anxiety level (*p*-value= 0.02) with adherence to treatment schedules for patients. There is a negative relationship between the stigma and the level of anxiety with treatment schedules in patients. **Conclusion:** The implication of the research is that stigma and anxiety levels affect the HIV/AIDS patients' treatment schedules. This research suggests that health workers need to provide more coping strategies and educational updates at the beginning of ARV (Antiretroviral) treatment along with the initiation of family gathering activities, and assess the anxiety symptoms of a patient during the therapy so that the patient will adhere to treatment schedules.

Keywords: Adherence, anxiety level, stigma, patients with HIV/AIDS

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INTRODUCTION

Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS) is a chronic disease that attacks the immunity of the human body (immunosuppression). The most dangerous conditions of patients with HIV/AIDS include weakened immune system. Over time, HIV attacks the body's CD4 cells which play a critical role in maintaining a healthy immune system (1–3). Patients with HIV/AIDS not only have problems with their physical condition, but they also face social problems that are quite concerning as a result of the stigma against this disease (4). The community creates an embarrassing situation for the HIV/AIDS patients as they treat them as an outcast of the society, as they think they a are responsible for the transmission of HIV / AIDS. As a result the patients with HIV/AIDS are isolated and get discriminatory behavior from the community (5,6). The situation of patients with HIV/AIDS are very complex, apart from having to face their illness, they also have to face the stigma and disgrace of the community, causing feelings of anxiety and negative reactions. Consequently, they do not take the medication regularly, especially if they are outside their environment because of fear of being exposed about their HIV status (7). The stigma felt by the patients with HIV/AIDS causes feelings of inadequacy, stress,

depression, guilt and, anxiety due to which they fail to access health services (8,9). This fear was considered to be the cause of HIV transmission.

Research conducted by Habibi and Supodo, (2020) on patients with HIV/AIDS in Kendari with a total of 48 respondents showed that there were 17 respondents (35.5%) patients with HIV/AIDS with a stigma of not adhering to ARV treatment and 31 respondents (64.5%) who adhered to ARV treatment (10). This study proved that patients with HIV/AIDS with a stigma were afraid to consume drugs in front of their friends or they were also afraid of being questioned about their illness in their work environment.

The roles of nurses in health services include looking after the biological needs, coping strategies, and providing social support and spiritual support to patients with HIV/AIDS which are very necessary during treatment. Nurses have an important role in stress management, especially in facilitating and directing constructive coping to accelerate the patient's adaptive response to the disease (2). Stigma is a significant barrier for patients with HIV/AIDS to prevent and treat HIV / AIDS (11). Nurses as counselors and educators for patients with HIV/AIDS play important role in coping strategies of patients with HIV/AIDS, including facilitating sources of self-potential so that acceptance response occurs according to the stages of Kubler-Ros, cognitive problem-solving techniques, and behavioral techniques, namely teaching behaviors that support healing (12). Psychosocial adaptive response (self-acceptance) to stigma generates feelings and anxious reactions (13). Patients with HIV/AIDS are expected to have constructive coping so that anxiety is reduced and will have an impact on positive social interactions with family, friends, and society (14). The reduced stigma in the community with HIV/AIDS patient will reduce the level of anxiety. This study aims to analyze the relationship between stigma and anxiety with adherence to treatment schedules for HIV/AIDS patients in Surabaya, Indonesia.

MATERIALS AND METHODS

This study used a correlational approach. This research was conducted at VCT Polyclinic of Menur Mental Hospital with a total of 97 respondents. In measuring the relationship, 3 questionnaires were used based on 3 variables in this study. To measure stigma, researchers used Berger HIV Stigma Scale in which the instrument used refers to measure the stigma felt by people living with HIV that has been developed based on some literature related to stigma and some psychosocial aspects of people living with HIV. The questionnaire consisted of 25 questions in the form of positive (favorable) and negative (unfavorable) questions. The instrument used a four-point (1-4) Likert scale (strongly disagree, disagree, agree, and strongly agree). The assessment of this instrument was done by converting the answers with the following scores: Strongly disagree = 1, Disagree = 2, agree = 3, and strongly agree = 4. Specifically for items 8 and 21, the scoring was done in reverse. The total score was done by adding up the scores of all items. If the score is higher, it can be said that the stigma is also high. The second questionnaire is regarding the level of anxiety based on Zung Self-Rating Anxiety Scale (ZSAS). ZSAS focuses on somatic complaints that represent anxiety symptoms. This questionnaire contained 20 questions describing anxiety symptoms. Each question item was assessed based on the frequency and duration of symptoms that occur, namely: (1) rarely or never, (2) sometimes, (3) often, and (4) almost always experiencing these symptoms. The maximum score is 80 and the minimum score is 20. The ZSAS has been widely used as an anxiety screening tool. The third questioner is adherence to treatment schedules using modified Morisky Medication Adherence Scale-8 (MMAS-8). MMAS-8 was categorized into 3 levels of medication adherence including high adherence (score 8), moderate adherence (score 6-7,) and low adherence (score < 6). The validated MMAS-8 questionnaire can be used to measure treatment adherence in diseases with long-term therapy, including HIV/AIDS. The advantages of the MMAS-8 questionnaire are easy, inexpensive, and effective to use to determine the adherence of patients with chronic diseases (15).

Sampling in this study used probability sampling with a simple random sampling technique, where the selection was made randomly based on the patient visiting the hospital, in which each population has an equal chance of being selected as a sample. In this case, sampling was carried out starting from October to December 2020 by using the inclusion criteria that have been determined by the researchers.

Characteristics of the population who have behaviors that are at risk of being infected with HIV/AIDS include injection in case of drug users, gays, transgender women, and female sex workers with a total of 97 patients consisting of 84 gays, 5 heterosexual, 5 housewives, 1 transgender, and 2 injection needle users. Antiretroviral (ARV) was given to HIV/AIDS patients with 30 doses of drugs for one month starting from their arrival. Data was collected for 1-2 weeks, during which the researchers have obtained the required sample. Data collection was carried out using Google Forms. When the prospective control respondents went to the VCT Polyclinic of Menur Mental Hospital Surabaya, the researchers asked them to fill the informed consent, so that they can ask questions about things that were not understood. If a potential respondent was willing to become a respondent, then the respondent was asked to sign the agreement sheet. Researchers recorded demographic data, stigma, level of anxiety, and treatment schedules adherence of the patients with HIV/AIDS. All instruments used have been tested for validity with a value > 0.90. Data analysis

used SPSS 26.0 with Spearman Analysis Test with the p < 0.05. The studies were conducted according to international and national ethical guidelines and ethical approval and informed consent were obtained from participants and/or legally acceptable representative/s. A statement of medical research ethics issued has been approved by the Health Research Ethics Commission (KEPK) of Menur Mental Hospital Surabaya Indonesia, in accordance with the number: 070/1013/305/2020.

RESULTS

Demographic data of patients with HIV/AIDS

Table I shows that most of the respondents were male (84.5%) with an average age of 31.88 years. An average of years in receiving ARV was 4.91 and an average length of suffering from HIV/AIDS was 6-10 years.

Table I. Demographic data of patients with HIV/AIDS

Variable		n (97)	Percentage
Sex			
	Man	82	84.5
	Woman	15	15.5
Age			
	18-30 years	60	61.9
	31-45 years	27	27.8
	46-60 years	10	10.3
Education level			
	Elementary school	3	3.1
	Junior high school	7	7.2
	Senior high school	56	57.7
	Diploma/University	31	32
Marital status			
	Not yet married	69	71.1
	Married	26	26.8
	Widow/widower	2	2.1
Job status			
	Jobless	2	2.1
	Pensioner	5	5.2
	Private	79	81.4
	Others	11	11.3
Comorbidities			
	Yes	32	33
	No	65	67
Long of suffering HIV/undergoing therapy			
	1-5 years	40	41.2
	6-10 years	24	24.7
	>10 years	33	34

Respondents who had behaviors that were at risk of being infected with HIV/AIDS included injecting drug users, gays, transgender women, and female sex workers in which there were 97 patients consisting of 84 gays, 5 heterosexuals, 5 housewives, 1 transgender, and 2 injection needle users. ARVs were given to HIV/AIDS patients with 30 doses of drugs or 1 month starting from their arrival.

The relationship between stigma and adherence to the treatment schedule

The data showed that from 97 people, there were 55 people with the category of having low adherence to treatment schedules as many as 2 people (3.6%), moderate adherence as many as 32 people (58.2%), and high adherence as many as 21 people (38, 2%). Respondents who experienced moderate stigma were 39 people categorized with low adherence to medication schedule as many as 6 people (15.4%), moderate adherence as many as 23 people (59%), and high adherence as many as 10 people (25.6%). Meanwhile, in high stigma, there were 3 people with low medication schedule adherence category as many as 2 respondents (66.7%), moderate adherence as many as 1 respondent (33.3%), and there was no respondent with high adherence. The results of the Spearman's rho statistical test showed that the correlation of stigma and adherence to the treatment schedule of HIV/AIDS patients showed a p=0.012 (p-value =<0.05) and the correlation coefficient of -0.254 in which it can be concluded that there is a relationship between stigma and treatment schedule adherence. Based on the 95% confidence interval, there was a relationship between stigma and adherence to treatment schedules with a correlation coefficient (r) of -0.524, which means that there is a strong negative relationship between stigma and adherence to treatment schedules. The higher the stigmatization received by the respondent, the lower the value of adherence to the treatment schedule.

The relationship between anxiety level and adherence to the treatment schedule

Table III shows there were 40 people with mild anxiety levels with the category of having low medication schedule adherence as many as 2 people (5%), moderate medication schedule adherence as many as 20 people (50%), and high medication schedule adherence as many as 18 people (45%). The respondents who had moderate anxiety levels were 49 people in which 5 people (10.2%) had low medication schedule adherence, 31 people (63.3%) had moderate medication schedule adherence, and 13 people (26.5%) had high medication schedule adherence. The respondents with high anxiety levels were 8 people in which 3 people (37.5%) had low medication schedule adherence and 5 people (62.5%) had moderate medication schedule adherence, and there was no respondent with high anxiety levels that had high medication schedule adherence. The relationship of the anxiety level of the respondents and adherence to the treatment schedule based on the results of the Spearman Rho test showed that the value of p is 0.002 (p-value <0.05) and the correlation coefficient is -0.308. Therefore, it can be concluded that there is a relationship between the level of anxiety and adherence to the treatment schedule among patients with HIV/AIDS.

Table III. The relationship between anxiety level and adherence with treatment schedule

Anxiety level	Treatment Schedule Adherence								Correlation co-efficient	p-value
	Low		Moderate		High		Total			
	f	%	f	%	f	%	f	%		
Low	2	5	20	50	18	45	40	100		
Moderate	5	10.2	31	63.3	13	26.5	49	100	-.308	$\rho = 0.02$
High	3	37.5	5	62.5	0	0	8	100		
Total	10	10.3	56	57.7	31	32	97	100		

The relationship between the level of anxiety of the respondents and adherence to the treatment schedule based on the results of the Spearman-rho test shows the value of p = 0.02 (ρ-value <0.05). Based on the result of the correlation coefficient (-.308), it can be concluded that there is a relationship between the level of anxiety and adherence to the treatment schedule in patients with HIV/AIDS.

DISCUSSION

Table II shows that out of the 97 patients at the VCT Polyclinic of Menur Mental Hospital Surabaya, most of them had a low stigma as many as 55 patients (56.7%), moderate stigma as many as 39 patients (40.2%), but there were 3 patients (3.1). %) who had a high stigma. In Surabaya, there were still 3 patients with high stigma, this can be as majority of the patients are gays community (Male Sex) who have deviant sexual behavior, as many as 84 people. The gay community is considered different from the usual and this community conflicts with the norms that exist in the society.

Table II. The relationship between stigma and adherence to the treatment schedule

Stigma	Treatment Schedule Adherence								Correlation co-efficient	P-value
	Low		Moderate		High		Total			
	f	%	f	%	f	%	f	%		
Low	2	3.6	32	58.2	21	38.2	55	100		
Moderate	6	15.4	23	59	10	25.6	39	100	-.254	$\rho = 0.012$
High	2	66.7	1	33.3	0	0	3	100		
Total	10	10.3	56	57.7	31	32	97	100		

The results of statistical tests show that there is a relationship between the stigma received by HIV patients and adherence to treatment with the p = 0.012 (ρ-value = <0.05) and the correlation coefficient of -.254. It can be said that this relationship is negative, i.e., the higher the stigma received by HIV patients, the lower the patient's adherence.

The results of statistical tests show that there is a negative relationship between stigma and adherence to treatment schedules. The higher the stigma felt by a patient with HIV/AIDS, the greater sense of concern that their HIV status will be revealed, so that the patient with HIV/AIDS tends to withdraw themselves from their surroundings.

At the time of processing data from respondents, researchers found that 68 respondents chose the answer to agree (3) in a questionnaire regarding trying hard to keep their HIV status secret. Habibi and Supodo (2020) stated that patients with HIV/AIDS tend to cover up their HIV status during interactions in public (10). The stigma is felt by patients with HIV/AIDS when they are aware of the humiliation against their group. They will agree with the stigma and apply it to themselves (internalizing the public stigma). This will lead to reduced or loss of self-esteem and self-efficacy. People with low self-efficacy, have a lower probability of accessing health services due to the feeling stigma (16).

The stigmatization among HIV/AIDS patient is not only directed to them, but also at the population or the general public who are suspected of being at high risk of being infected with HIV and the people around them. This stigma increases the risk of being infected with HIV and so they avoid social gatherings, that they find uncomfortable, including accessing health services (17). Adherence is a form of behavior that arises as a result of the interaction between health workers and patients so that patients understand the plan with all its consequences and agree to the plan and implement it (18). Adherence to the treatment schedule according to the rules of treatment so that HIV patients take medication in time until the end of the treatment period. In terms of the relationship between ARV therapy in People living with HIV /AIDS (PLWHA), adherence is intended as a collaborative process between the client and the health service provider. Patients are conditioned to play a more active role following treatment and are committed to following the treatment given (14,19).

Adherence to the treatment schedule is very important and should be monitored and evaluated regularly at each visit. The failure of ARV therapy is often caused by the patient's nonadherence in taking ARVs. To suppress optimal viral replication, a compliance rate of at least 95% is required (20). If the level of the drug in the blood of PLWHA becomes too low, the virus in the body can become resistant to the ARV drugs used (21). If this happens, then the drugs consumed will be ineffective against this new type of virus. Some experts think that if a person with HIV forgets to take the medication more than twice a month forgets, a resistant strain of the virus can emerge. When this happens, therapy will begin to fail and the patient may have to replace all the drugs that have been taken (22). Good medication adherence refers to the action of taking medication as a treatment and an agreement between the patient and the health worker. Poor medication adherence includes skipping doses or taking medication inappropriately and not according to the medication schedule or regimen. The risk of therapy failure occurs when a patient does not comply with the treatment schedule and often forgets to take medication (23,24).

Another theme that attracts attention is the social stigma associated with illness. Studies report show that shame has contributed to nonadherence. It has been reported that regarding shame associated with drug use, patients with low adherence are more likely to feel uncomfortable (25). Disobedience behavior is shown as a form of seeking more attention from the surrounding environment. Some studies show that this occurrence will be more common among children receiving treatment (26).

The trans gender women in this study showed that adherence to medication was very poor. Many factors that influence this condition include cultural conditions and the situation of people whose existence is not accepted in the society. Other factors are the incidence of verbal and non-verbal violence, social exclusion, restrictions on their activities, negative views on their behavior and life, lack of support system, and lack of access to health service, lack of risk-prevention behavior, and low social support from the community after they are diagnosed. Sometimes, it is also found that they limit themselves from the surrounding environment. Although they are also active in having sex with their partners, their behavior and relationship patterns have begun to change with the use of condoms that are safer during sexual intercourse (27). This finding shows that the culture of the surrounding community affects their lives after being diagnosed with HIV. Changes in views and stigmatization received by people living with HIV are also considered as punishment for their behavior. The findings are similar to those reported by other studies elsewhere. The psychologically adaptive response of a patient with HIV/AIDS in the form of self-acceptance of the disease will generate various feelings and stress reactions including frustration, anxiety, anger, denial, shame, grief, and uncertainty leading to adaptation to disease (3). Anxiety and fear are not only caused by the illness, but also by the pressure of the people who often give certain symbols to their illnesses (27).

The finding showed that patient feel anxious when they are just diagnosed because they are concerned about their future health condition, and also the response from their family and environment regarding their illness, and their work environment. Anxiety, fear of death, stigmatization, and discrimination arise due to negative perceptions about HIV/AIDS, feelings of fear, and excessive avoidance in patients. Patients diagnosed with HIV/AIDS experience severe anxiety, when they are diagnosed with AIDS. Based on many research results, they have not been able to accept these conditions and facts that they are infected with HIV/AIDS. After several months with some appropriate approaches, they can only accept these facts and start trying HIV therapy (28). In this study. it was also found that there were several effects of anxiety experienced by patients, including mental disorders, lack of concentration, depression, feelings of guilt, closing themselves off, disorganized

thoughts, loss of perceptual abilities, phobias, illusions and hallucinations, anxiety, anger, and acts of suicide.

CONCLUSION

Stigma and anxiety are often felt by patient with HIV / AIDS with the length of time of undergoing ARV treatment at VCT Polyclinic of Menur Mental Hospital Surabaya for 0-5 years. This is because a patient with HIV/AIDS is still in the process of adapting to cope with the disease and its treatment. The psychological and social pressures in the early days of treatment cause anxiety for a patient with HIV / AIDS due to the long-term use of drugs and the fact that HIV / AIDS cannot be cured. Besides, the perceived stigma creates a feeling of fear of being excluded and losing the job. The feeling of the stigma that is felt by the patient with HIV / AIDS and the level of anxiety affect adherence to the treatment schedule for a patient with HIV/AIDS.

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