ISSN 2354-7642 (Print), ISSN 2503-1856 (Online)
Jurnal Ners dan Kebidanan Indonesia
Tersedia *online* pada:
http://ejournal.almaata.ac.id/index.php/JNKI

INDONESIAN JOURNAL OF NURSING AND MIDWIFERY

The Effects of Social Support, Participation in Supporting Network Communities and Stigma and Discrimination of Surrounding Environment against Self-Stigma on Housewives PLWHA in Special Region of Yogyakarta

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Abstrak

Sebanyak 76% kasus HIV / AIDS di Daerah Istimewa Yogyakarta ditularkan melalui kontak seksual. Kondisi ini mempengaruhi 407 ibu rumah tangga yang terinfeksi HIV dari suaminya. Perasaan cemas, marah, dan kecewa yang dirasakan oleh penderita HIV / AIDS, perawatan medis, diskriminasi, dan tanggapan publik terhadap penyakit ini sering menyebabkan orang yang hidup dengan HIV / AIDS (ODHA) hidup dalam kecemasan, stres, depresi, dan kekurangan. dukungan sosial sehingga orang cenderung menghindari atau menarik diri dari lingkungan mereka. Oleh karena itu, pada akhirnya, ini menyebabkan hanya sejumlah kecil orang yang hidup dengan HIV / AIDS (ODHA) yang dapat mengakses layanan kesehatan untuk terapi ARV. Metode penelitian ini adalah deskriptif analitik dengan pendekatan cross-sectional yang bertujuan untuk menganalisis faktor-faktor yang mempengaruhi stigma diri pada ibu rumah tangga ODHA di Daerah Istimewa Yogyakarta. Analisis bivariat yang digunakan adalah analisis chi-square sedangkan analisis multivariat yang digunakan adalah regresi logistik. Hasil penelitian menunjukkan bahwa dukungan sosial merupakan faktor yang paling dominan mempengaruhi stigma diri. Dianjurkan bagi pemerintah untuk meningkatkan penyediaan dukungan sosial bagi orang yang hidup dengan HIV / AIDS (ODHA) dengan menyediakan layanan perawatan dan perawatan yang mudah diakses dan sesuai dengan kebutuhan ODHA serta mendidik masyarakat dengan baik tentang HIV / AIDS. AIDS meningkatkan kesadaran ODHA tanpa diskriminasi.

Kata kunci *: Stigma-Diri, ODHA (ODHA)*

Abstract

As many as 76% of HIV/AIDS cases in Special Region of Yogyakarta are transmitted through sexual contact. This condition affects 407 housewives who are infected with HIV from their husbands. The feeling of anxiety, anger, and disappointment felt by HIV/AIDS sufferers, medical care, discrimination, and public response to this disease often leads to people living with HIV/AIDS (PLWHA) are living in anxiety, stress, depression, and lack of social support so that people tend to avoid or withdraw from their environment. Therefore, in the end, this causes only a small number of people living with HIV/AIDS (PLWHA) who can access the health services for ARV therapy. This research method is analytical descriptive with cross-sectional approach which aims to analyze the factors that influence self-stigma on housewives PLWHA in Special Region of Yogyakarta. Bivariate analysis used was chi-square analysis whereas the multivariate analysis used was logistic regression. The result shows that social support is the most dominant factor influencing self-stigma. It is advisable for the government to improve the provision of social support to people living with HIV/AIDS (PLWHA) by providing care and treatment services that are

easily accessible and appropriate to the needs of PLWHA as well as educate the public properly about HIV/AIDS raising awareness of PLWHA without discrimination.

Keywords: Self-Stigma , PLWHA (people living with HIV/AIDS)

Article info:
Article submitted on Marcj 18, 2018
Articles revised on April 28, 2018
Articles received on May 30, 2018
DOI: http://dx.doi.org/10.21927/jnki.2018.6(2).124-131

INTRODUCTION

AIDS is an infectious disease that damages the human immune system, making it more susceptible to other types of infectious diseases. People who develop this disease will become carriers and transmitters of HIV during their lifetime. This is what causes adverse effects that affect the physical, psychological and social for people living with HIV/AIDS (PLWHA).[1]

The feeling of anxiety, anger, and disappointment conveyed directly at disease complaints; medical treatment; discrimination and public response to this disease are often experienced by people with HIV/AIDS. As the result, most of people living with HIV/AIDS (PLWHA) exhibit changes in psychosocial characters (living in anxiety, stress, depression, and lack of social support), so that sufferers tend to avoid or withdraw from their environment.[2]

According to WHO/UNAIDS 2010, there were 33.4 million people with HIV/AIDS. A total of 15.7 million (47%) of whom are women and 2.1 million children aged less than 15 years. HIV can be transmitted in various ways. In Indonesia, the mode of HIV transmission frequently occurs through unsafe sexual contact and injecting drugs. Sexual transmission of HIV causes an impact on the increase in the number of HIV-infected mothers from their husbands.[3]

Another form of stigma is that people living with HIV/AIDS (PLWHA) develop a negative perception of themselves. This stigma is related to the illness they are suffering that causes a severe psychological effect on themselves. In some cases, it encourages depression, lack of self-esteem and despair. This condition hampers HIV/AIDS prevention efforts because stigma increases social isolation and depression or barriers to access to health services for PLWHA. People living with HIV/AIDS (PLWHA) tends to be reluctant to open up to the surrounding environment, including dampening the intention to access health services.[4] In addition, the risk of suicide in people with AIDS is high due to mental depression experienced.

From several occasions obtained by the researcher to conduct a preliminary survey of research, data obtained from Provincial Health Office of Yogyakarta until June 2015 showed that PLWHA women who entered in HIV care are a total of 864 people with eligible medical for ARV is 723 (83.7%) of patients while those who have not met medical requirements are 141 (16.3%) patients. Of the 723 eligible patients receiving antiretroviral therapy, 686 (94.8%) of patients had received antiretroviral therapy, and from a number of patients receiving antiretroviral therapy there were 45 (6.6%) patients referred out, 139 (20.3%) patients died, and 176 (25.6%) patients were absent from ARV therapy and stopped. The number of HIV/AIDS patients who were considered disobedient in taking ARVs at HIV/AIDS referral hospitals in Yogyakarta from January to June 2015 continued to increase rapidly. In June there were 264 (80.9%) women were considered disobedient

in taking antiretroviral. By not adhering to the rules of antiretroviral therapy, viral replication and disease progression in reducing opportunistic infections and mortality cannot be inhibited. Increasing the number of PLWHA women who are not adherent to antiretroviral therapy is proportional to the increase in the incidence of OI. Increased number of HIV-positive women infected with TB as OI in HIV-infected patients seen in January 2015 to June 2015, of 115 HIV-TB patients in January 2015 increased to 123 patients in June 2015.

The low number of people living with HIV/AIDS (PLWHA) who access the HIV/AIDS services and the high incidence of non-adherence to antiretroviral therapy indicates low self-esteem and hopelessness that indicates self-stigma in people living with HIV/AIDS (PLWHA). This makes the authors want to know what factors are related to self-stigma on housewives PLWHA in Special Region of Yogyakarta. The formation of self-stigma in PLWHA is motivated by the condition of the individual as well as the surrounding environment. In some cases, the stigma encourages depression, lack of self-esteem and despair. This condition hampers HIV/AIDS prevention efforts because stigma increases social isolation and depression or barriers to accessing health services for PLWHA. PLWHA tends to be reluctant to open up to the surrounding environment, including discouraging the intention to seek treatment in health services.[4] To see the background of self-stigma in people living with HIV/AIDS (PLWHA), therefore, the problem formulation can be summarized as follows: “what factors influence self-stigma on housewives PLWHA in Special Region of Yogyakarta?”

MATERIALS AND METHOD

This research used quantitative method with cross-sectional approach. The quantitative approach used was observational with analytic survey research method. The population of this study is housewives PLWHA who live in Special Region of Yogyakarta which amounts to 407 people. Based on the inclusion and exclusion criteria, there were 97 PLWHA households used in this study. The inclusion criteria of sample is PLWHA who infected from her husband and PLHW who agree to be respondent. The samples were obtained by accidental sampling technique. To determine the most influential factor on self-stigma on people living with HIV/AIDS (PLWHA), then each independent variable and dependent variable first was analyzed using chi-square, then the related variables were analyzed using logistic regression.

RESULT AND DISCUSSION

This research observed 97 housewives who were infected with HIV/AIDS. The data were collected by using questionnaire.

Table 1. The Characteristics of Respondents Distribution

Variables	Frequency	Percentage (%)
Age		
18-40 years old	72	74.23
41-60 years old	25	25.77
Education		
Not finishing elementary school	1	1.03
Elementary school	25	25.77
Junior high school	26	26.80
High school/vocational school	33	34.03
Higher institution	12	12.37
Occupation		
Working	69	71.13
Not working	28	28.87

(Source: Primary Data, 2016)

Table 1 shows that as many as 97 respondents are mostly aged 18-40 years old, the latest education is high school/vocational school and in addition to being housewives, they are also actively working to earn income.

Table 2 shows that the majority of respondents have low self-stigma, social support,

Table 2. Self-Stigma, Social Support, Participation in Supporting Network Communities, External Stigma and Discrimination of Respondents Distribution

Variables	Frequency	Percentage (%)
Self-stigma		
High	36	37.1
Low	61	62.9
Social Support		
Supporting	82	84.5
Less supporting	15	15.5
Participation in Supporting Network Communities		
Active	66	68.0
Inactive	31	32.0
External Stigma and Discrimination		
High	23	27.3
Low	74	76.3

(Source: Primary Data, 2016)

and are active in supporting network communities and also have experienced external stigma and discrimination even in low categories.

To examine the relationship between social support and self-stigma, a chi-square test was performed in which the result can be seen in the following table:

Table 3. The Correlation of Social Support and Self-Stigma

Social Support	Self-Stigma				Total	
	Low		High			
	f	%	f	%	f	%
Less supporting	2	13.3	13	86.7	15	100
Supporting	59	72.0	23	28.0	82	100
Asymp. Sig. (2-sided) = 0.000			P value = 18.668			

(Source: Primary Data, 2016)

Table 3, 4, and 5 show that all the independent variables in this study proved to have a correlation with the dependent variable.

Table 4. The Correlation of Participation in Supporting Network Communitiesand Self-Stigma

Participation in Supporting Network Communities	Self-Stigma				Total	
	Low		High			
	f	%	f	%	f	%
Inactive	10	32.3	21	67.7	31	100
Active	51	77.3	15	22.7	66	100
Asymp. Sig. (2-sided) = 0.000			P value = 18.313			

(Source: Primary Data, 2016)

Table 5. The Correlation of External Stigma and Discrimination and Self-Stigma

External Stigma and Discrimination	Self-Stigma				Total	
	Low		High			
	f	%	f	%	f	%
Low	55	74.3	19	25.7	74	100
High	6	26.1	17	73.9	23	100
Asymp. Sig. (2-sided) = 0.000			P value = 17.493			

(Source: Primary Data, 2016)

It is seen from each significance value of the variables is less than 0.05.

Self-stigma is a negative self-assessment/ judgment. The findings of this study also show that 37.1% of respondents have high self-stigma. This condition illustrates that the respondent has a sense of inadequacy, weakness, low self-esteem, considers the unfortunate and different from the people as a result of HIV disease he suffered. The results of this study are not much different from the results of studies conducted in Schizophrenia patients in Mumbai which stated that the most commonly seen form of stigma was inferiority due to low knowledge about the disease and the existence of stigma and discrimination from the family and the environment around the patient.[5] In one study mentioned that self-stigma occurs because of the perception that they are

Table 6. The Influences of Independent Variables towards the Dependent Variables Values

Variables	B	S.E.	Wald	Df	Sig	Exp (B)	95% C.I.for EXP(B)	
							Lower	Upper
Participation in Supporting Network Communities	-1.673	.615	7.399	1	.007	.188	.056	.626
Social Support	-2.379	.914	6.769	1	.009	.093	.015	.556
External Stigma and Discrimination	1.575	.769	4.194	1	.041	4.830	1.070	21.800
Constant	4.032	2.032	3.938	1	.047	56.363		

perceived as "the embarrassing enemy, the disease" of society or those who disobey the prevailing norms of society and religion. This stigma will lead to implications and discrimination to oneself, certain groups, families and parties related to their lives.[6]

In this study, it is known that people with HIV who have high self-stigma have a tendency to be inactive in the activities of peer support groups. The results of this study are in line with the results of previous studies which stated that as many as 71% of the quality of life of people with HIV is good because of the existence of a peer support system. Confidence is often used to measure quality of life. According to Self Perceived Quality of Life, the need for safety and security, feeling loved and possessed, feels valued, feels proud, feels respected, and has confidence, is part of SPQL. How is the response of PLWHA to HIV positive status, can be seen from the nature of PLWHA who are not inferior, HIV status does not interfere with the attitudes and behavior of PLWHA, there is no desire to stay away from others, do not stigmatize themselves by separating goods, and do not have anxiety in living life.[7]

Peer support groups are groups in which two or more people infected or directly affected by HIV gather and support one another. For many people with HIV in many regions of the world, support groups are the only place where they feel comfortable, can get out of isolation, be kept confidential, safe and supported. Especially in developing countries, where services for people with HIV are still weak or even nonexistent, support groups play a large role in efforts to tackle HIV / AIDS as a whole. Support groups are a place to provide support and care and become a place where education and dissemination of information about HIV / AIDS occurs.[8]

Activities in the Peer Support Group have also reduced stigma and discrimination. In the study, it was stated that more than 90% of peer support helped people with HIV and AIDS who get stigma and discrimination. This form of strong stigma and discrimination makes it difficult for PLHAs to open up and be difficult to reach. This Peer Support Program can be seen as an entry point and / or complementary in reducing the impact of stigma and discrimination in the community.[7]

About 44% of respondents in the previous study participated in peer support groups organized by care facilities, which provided them with effective psychosocial support and could enable them with skills for social disclosure.[9,10]

Almost all respondents of this study have received external stigma and discrimination from family, community, and health workers. External stigma and discrimination experienced by respondents in the form of being shunned, rejected, obtaining moral justice, stigma due to relations and the destruction and violation of human rights. This research is in line with previous research which states that the form of stigma and discrimination in the form of social isolation, dissemination of HIV status and rejection in various spheres of community activities such as the world of education, the world of work, and health services are forms of stigma experienced by PLHAs. The existence of this stigma causes people with HIV and groups at risk of being afraid to take an HIV test because if it is revealed the results are reactive causing them to be ostracized. HIV positive people are afraid to reveal their HIV status and decide to delay treatment if they are sick.[11]

Restrictions on opportunities that can affect all aspects of life for PLWHA, starting from social interaction, opportunities to obtain education and employment, health services, traveling, etc. will cause a lack of appropriate health information. So that people with HIV tend to perceive as a state of illness in accordance with the concept of ordinary people.[12]

Stigma and discrimination makes anxiety and PLWHA fear to open their status. In one study

it was also stated that vulnerable populations were afraid to undergo diagnostic tests caused by the threat of stigma and discrimination. This makes it a barrier for PLWHA and vulnerable populations to reach the availability of health services.[11.13]

Support or elimination of stigma from people around PLWHA will also have an impact on increasing utilization of health services. Social support makes HIV sufferers not feel alone, feels loved and they are more likely to take advantage of health services. Utilization of health services by PLWHA allows for increased knowledge, sharing information about HIV / AIDS and increasing adherence to antiretroviral (ARV) therapy. Openness and comfort felt by ODHA makes it easier for them to receive information to improve the quality of life so that people with HIV do not have a negative stigma on themselves.[14]

Social support variable is the most dominant variable that affects self-stigma, it is seen from the value of B (2.379) of the variable is the highest than the value of B from other variables. The multivariate test by using logistic regression in this variable also results in a significance value of 0.009, which means less than 0.05, with a beta-coefficient of -2.379. Therefore, it can be concluded that there is a correlation of social support and self-stigma with the direction of a negative relationship. This means that the group of respondents who get social support tend to have a low self-stigma, while the group of respondents who lacked social support tend to have a high self-stigma. The results of this study are in line with previous research which states that there is a very significant positive correlation of social support and self-esteem in adolescents with lupus disease. The higher the social support will be the higher the self-esteem in adolescents with lupus disease, and vice versa.[15]

Social support is the comfort, attention, appreciation, acceptance, or assistance that individuals obtain from families or others who can be relied on to improve the adaptability of the individual in overcoming challenges, stress, and suffering.[16] Based on this opinion it can be said that social support is not only comes from people closest to whom has been known by the sufferer like family, friends, and other relatives. But social support can also come from other people such as social workers residing in NGOs, health workers, clergy and clerics, and members of certain communities who have never been known to sufferers.

Social support is accepted by individuals in five forms, i.e. emotional support, award support, instrumental support, information support, and social networking support.[16] Social support is able to provide physical and psychological comfort to the individual, and it can be seen from how social support affects the events and effects of the stress condition.

HIV/AIDS patients are not only experiencing pressure due to the HIV virus that attacks the immune system, but they are also faced with stigma and discrimination. Peopleliving with HIV/AIDS (PLWHA) often get the stigma caused by the virus that infects them.[15] PLWHA is often referred to as a person who suffers from sexual or gay deviations, mischievous women, and miscommunication. Through the stigma, people living with HIV/AIDS (PLWHA) are then ostracized and unwittingly that the act has actually affected their psychological condition. This leads PLWHA to stress, depression, despair and self-closing conditions. They will choose to conceal its health status from family, friends or close relatives. Therefore, this condition makes people living with HIV/AIDS (PLWHA) not able to get the support that should be obtained.[17]

Peopleliving with HIV/AIDS (PLWHA) needs support to make their life expectancy longer. With the social support, it will create a conducive environment that can provide motivation and provide new insight for people living with HIV/

AIDS (PLWHA) in facing their life.(16) This social support can minimize the psychosocial pressure felt by people living with HIV/AIDS (PLWHA), so they can have a better lifestyle and can provide a response which is more positive to the social environment. In addition, with this social support, they will feel more appreciated, loved, and being a part of the community. Consequently, people living with HIV/AIDS (PLWHA) will not feel discriminated that it will be positive for their health.

High social support will also accelerate the resolution of problems that are faced by the individuals including the illness they suffered from. Moreover, people suffering from chronic diseases can better adapt to their chronic conditions if they have family members who actively participate in enforcing regimens, encouraging them to become self-sufficient, and responding to their needs in a good and thorough way.(16)

Social support received by HIV/AIDS sufferers as well as in most cases can include some forms of support, including: emotional support, instrumental/ material support, award support, information support, and social networking. With the support that individuals get, they will be able to increase their self-confidence and motivate the patients to be better, as individuals with high social support tend to appreciate their positive life experiences, have higher self-esteem and more life optimistic compared to the individuals with low social support.

CONCLUSION AND SUGGESTION

The formation of self-stigma in people living with HIV/AIDS (PLWHA) is influenced by several factors, including the participation of HIV/AIDS patients in supporting network communities, social support, external stigma and discrimination. Social support is the most influential factor in the formation of self-stigma in people living with HIV/AIDS (PLWHA). It is therefore necessary to increase the provision of social support to people living with HIV/AIDS (PLWHA) by providing care and treatments services that are easily accessible and appropriate to the needs of PLWHA, increasing the provision of appropriate information about HIV/AIDS to the wider community to raise awareness of PLWHA without discrimination, increasing the number and variety of activities in the advisory services, particularly in peer support groups so that all people living with HIV/AIDS (PLWHA) can reach and actively participate in PLWHA peer support group activities to realize the powered PLWHA and have high quality life.

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