

Impact of Non-Governmental-Based Supporting Group toward Resilience Level among People with HIV AIDS in Indonesia

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ABSTRACT

The problem faced by the government is the limitation to support PLWHA to enhance their mental health status. The non-governmental-based supporting group may have an impact on PLWHA's resilience due to their psychosocial problems. The purpose of this study was to explore the resilience levels among people with HIV/AIDS (PLWHA) who are members of a non-governmental-based supporting group. This study used a quantitative design with a descriptive explorative approach — a hundred PLWHA, who have registered and followed the non-governmental supporting group in Jember, Indonesia during the last period of 2018 following this study by using a purposive sampling technique. The Brief Resilience Scale questionnaire was used to collect data. Data was collected in June - July 2019. Data were analyzed by descriptive explorative approach with 95% of CI and data were shown in the frequency table. The results of this study showed that 3% of the respondents' resilience has low resilience category, 56% has normal resilience, and 41% has high resilience level after 6 months following the supporting group. Support from members of the supporting group as an external factor made respondents more resilient. Resilience for PLWHA should be further enhanced to help PLWHA survive better and be able to face difficulties.

Keywords: resilience; PLWHA; HIV; supporting group

INTRODUCTION

An increasing number of people living with HIV AIDS (PLWHA) cases (Kurniawan et al., 2021) have an impact on complex psychosocial problems. Generally, for the first time knowing that someone who has HIV/ AIDS feels unsure, shocked, and denial accompanied by anger and anxiety, there are symptoms of high anxiety and depression. Psychological problems continue to feel useless, think that the future is black, can not do anything for himself or family, and think that he will not have access to work and have limitations in social interaction (Rahakbauw, 2016). Nearly 99% of PLWHA experienced stress or severe depression when they find out they have AIDS. Many PLWHAs also cannot accept the fact that they infected HIV, so that leads to depression (Ardana, 2018).

The previous study found resilience to be a protective factor from the emergence of depression, anxiety, fear, feelings of helplessness, and various other negative emotions so that it has the potential to reduce the physiological effects that may arise (Rosyani, 2012). For HIV positive patients, resilience helps relieve the burden or stressor of sufferers from the physical pain they experience where resilience can act as a psychological immune system. Similarly, ODHA's resilience is believed to be able to adapt and control life's difficulties (Hardiyani, 2015).

Supporting group (SG) is a form of support group where the members utilize the same stressful experience as a process of mutual assistance. Supporting groups themselves have the role to help and provide emotional support (Manurung et al., 2021), share negative feelings, the development of the principle of helper-therapy, and provide opportunities for social comparison. The existence of the SG is very helpful for dealing with similar stressors and is expected to lead to validation, normalization of experience, reduction of social and emotional isolation, and a sense of togetherness (Lutfiana & Surjaningrum, 2010). One form of supporting groups in Jember, Indonesia, is non-governmental organization (NGOs) that oversee PLWHA (Kurniawan & Ardiana, 2021), especially support the government to against HIV AIDS and its psychosocial impact for the PLWHA. The supporting group is active in

supporting PLWHA, especially in overcoming psychological problems. The supporting group gives some psychosocial support for the PLWHA at least once a month. One of the problems may facing by government is limitation to support PLWHA to enhance their health status through continuing support activities. It may have an impact to PLWHA resilience due to their psychosocial problems through its activities.

The purpose of this study was to explore the resilience of people living with HIV who are members of a non-governmental-based supporting group in Jember, Indonesia.

METHOD

This study used a quantitative design with a descriptive explorative approach. A hundred PLWHA followed this study (according to minimum sample for descriptive study (Fraenkel & Wallen, 2006)) and collected by using a purposive sampling technique. The respondents in this study are PLWHA, who have registered and followed the registered non-governmental supporting group called "LASKAR" foundation (Langkah Sehat dan Berkarya) of Jember, Indonesia during the last period of 2018 and at least 1 month following time.

Data was collected door to door by using The Brief Resilience Scale (BRS) questionnaire in June - July 2019. The respondents directly fulfilled the questionnaire after we explained the study. The questionnaire in this study was made by Smith et al. (2008), The Brief Resilience Scale consists of 6 statement items (question number 1,3,5 was favorable and 3 others was unfavorable) measured on a Likert scale, from "strongly disagree", "disagree", "neutral", "agree", and "strongly agree" and all statement indicator was perseverance. Scale scores indicate that the higher the answer score, the lower the resilience. Data were analyzed by descriptive explorative approach with 95% of CI. Resilience level is divided into low resilience if the BRS score is 1.00-2.99; the normal resilience score is 3.00-4.30, and high resilience if the BRS score is 4.31-5.00.

Ethical clearance was declared by the Health Research Ethics Committee/*Komisi Etik Penelitian Kesehatan* (KEPK) at the Faculty of Dentistry Universitas Jember with registered number 462/UN25.8/KEPK/DL/2019.

RESULT

Level of Resilience based on Respondents' Characteristics

According to table 1, the age of normal to high resilience that is aged 30-49 as much as 54%. Genders with a high level of resilience are male, 22 respondents (22%), and normal resilience levels are also found in men with 34 respondents (34%). In contrast, those with low resilience are in the female sex of 3 respondents (3%). The majority of high, normal, and low resilience levels are in the last education of junior high school, for a high resilience rate of 15 respondents (15%), a normal resilience rate of 21 respondents (21%), a low resilience rate of 2 respondents (2%). The businessman is at normal resilience 27 respondents (27%). Marital status with normal resilience level is 47 respondents (47%). The majority of the level of normal resilience seen from the family status as a father that is equal to 26 respondents (26%). The level of resilience is normal, and the majority are in <6 months, with 54 respondents (54%). The results of the analysis on the resilience of people living with HIV AIDS who are members of a supporting group in Jember show that the majority of respondents' resilience is in the normal to high category is 94 respondents (94%) after they followed SG more than 6 month.

Table 1. Level of Resilience based on Respondents' Characteristics (n=100)

Characteristics	Resilience Level			Total n (%)
	Low n (%)	Normal n (%)	High n (%)	
Age				
20-29	0 (0.0)	29 (29.0)	16 (16.0)	45 (45.0)
30-39	3 (3.0)	21 (21.0)	22 (22.0)	46 (46.0)
40-49	0 (0.0)	6 (6.0)	3 (3.0)	9 (9.0)
Sex				
Male	0 (0.0)	34 (34.0)	22 (22.0)	56 (56.0)
Female	3 (3.0)	22 (22.0)	19 (19.0)	44 (44.0)
Education				
Elementary school	0 (0.0)	19 (19.0)	13 (13.0)	32 (32.0)
Junior high school	2 (2.0)	21 (21.0)	15 (15.0)	38 (38.0)
Senior High school	1 (1.0)	16 (16.0)	13 (13.0)	30 (30.0)
Occupation				
Government worker	0 (0.0)	7 (7.0)	6 (6.0)	13 (13.0)
Businessman	0 (0.0)	27 (27.0)	17 (17.0)	44 (44.0)
Farmer	0 (0.0)	3 (3.0)	6 (6.0)	9 (9.0)
Housewife	3 (3.0)	19 (19.0)	12 (12.0)	34 (34.0)
Marital Status				
Marriage	3 (3.0)	45 (45.0)	33 (33.0)	81 (81.0)
Single	0 (0.0)	10 (10.0)	9 (9.0)	18 (18.0)
Divorce	0 (0.0)	1 (1.0)	0 (0.0)	0 (0.0)
Family-member status				
Father	0 (0.0)	26 (26.0)	18 (18.0)	44 (44.0)
Mother	3 (3.0)	20 (20.0)	15 (15.0)	38 (38.0)
Child	0 (0.0)	10 (10.0)	8 (8.0)	18 (18.0)
Duration following SG				
>6 month	3 (3.0)	54 (54.0)	40 (40.0)	97 (97.0)
<6 month	0 (0.0)	2 (2.0)	1 (1.0)	3 (3.0)
Total	3 (3.0)	56 (56.0)	41 (41.0)	100 (100)

Respondents' Responses to the Brief Resilience Scale

Table 2. Distribution of Respondents' Responses to the BRS Question Item (n=100)

No.	Question*	Responses to the Brief Resilience Scale				
		Strongly agree n (%)	Agree n (%)	Neutral n (%)	Disagree n (%)	Strongly disagree n (%)
1.	I tend to bounce back quickly after hard times	28 (28.0)	62 (62.0)	7 (7.0)	0 (0.0)	3 (3.0)
2.	I have a hard time making it through stressful events	3 (3.0)	3 (3.0)	8 (8.0)	59 (59.0)	27 (27.0)
3.	It does not take me long to recover from a stressful event	21 (21.0)	64 (64.0)	13 (13.0)	1 (1.0)	1 (1.0)
4.	It is hard for me to snap back when something bad happens	2 (2.0)	1 (1.0)	12 (12.0)	70 (70.0)	15 (15.0)
5.	I usually come through difficult times with little trouble	25 (25.0)	62 (62.0)	10 (10.0)	2 (2.0)	1 (1.0)
6.	I tend to take a long time to get over setbacks in my life	1 (1.0)	1 (1.0)	4 (4.0)	59 (59.0)	35 (35.0)

*According to BRS question from Smith et al. (2008)

According to table 2, the majority answer of question number one in BRS is "agree" of 62 respondents. Question number two, as many as 59 respondents answered: "disagree". Question number three, most respondents answered "agree" about 64 respondents. The majority response of question number four is "disagree", as many as 70 respondents. Sixty-two respondents answered "agree" to the fifth question. Furthermore, the last question, more than half PLWHA or 59 respondents answered: "disagree".

Table 2. Respondents' Resilience Score Analysis (n=100)

Variable	Median	Min	Max	Q1	Q3
Resilience score	25	6	30	24	26

*According to Kolmogorov-Smirnov test, $p < 0.001$; 95% of CI

According to table 3, the median resilience score of PLWHA who following SG is 25, with lowest score is 6 and highest score is 30. In addition, the resilience score is approaching maximum score of the BRS. It means that PLWHA who following SG have an impact on their resilience.

DISCUSSION

One form of supporting groups in Jember, Indonesia, is NGOs that oversee PLWHA, especially support the government to against HIV AIDS and its psychosocial impact for the PLWHA. The supporting group is active in supporting PLWHA, especially in overcoming psychological problems. The supporting group gives some psychosocial support for the PLWHA at least once a month. One of the problems may facing by government is limitation to support PLWHA to enhance their health status through continuing support activities. In this study, NGO-based SG have an impact to PLWHA resilience level due to their psychosocial problems through its activities. The resilience level of PLWHA showed on normal to high category after they followed SG more than 6 month. The normal to high level of resilience manifest the role of SG.

In this study, the average age of respondents was 30 years old. Age is a measure of someone in assessing maturity in development. Age 30-43 years is a productive age in which the productive age is very susceptible to transmit HIV and high risk of contracting HIV because, in this group, sexual activity is quite high (Kusuma, 2011). At the age of 30 years, at which age it is emotionally and physically ready to lead an independent life and give a picture of good resilience.

The largest population infected with HIV is men. A high level of resilience is found in the male sex of 22 respondents (22%), and a normal resilience rate of 34 respondents (34%), while those with low resilience rates are in women as much as three respondents (3%). In line with the condition in Indonesia, which also states that there are more men with HIV AIDS than women with a ratio of 2:1. It is possible because men's behavior at more risk, so they are vulnerable to infection (Indonesia, 2018).

People living with HIV who are members of the supporting group in Jember had the most recent education at junior high school as many as 38 respondents (38%) and at least had the latest education at senior high school as many as 30 respondents (30%). The majority of resilience levels were in the junior high school level, with 21 respondents (21%), while the resilience level was low, with two respondents (2%). The latest education is one of the measures of positive behavior change, and it is reflected in the status of education level (Ariyanti et al., 2019). The higher their education, the easier to receive information and quickly determine and change to better behavior (Apriastuti, 2013). The analysis obtained from this study shows that the majority of PLWHA who have junior and senior high school education influenced good thinking patterns, causing resilient states.

Respondents with low resilience were few (3%). Based on the results of the analysis, all three were female; the last education was junior high school, mothers, was married, and were not working/wives. Gender also becomes an internal factor that influences the level of resilience in individuals (Azzahra, 2017). Female respondents have a more significant contribution to social support and resilience than men. In line with previous studies, women have stronger resilience, so it becomes an essential factor in long life and survival in the future when compared with men (Azzahra, 2017). The latest education is one of the measures of positive behavior change and reflected in the status of last education. The higher-level education, the easier to receive information and quickly determine and change better behavior (Apriastuti, 2013).

The low level of resilience of PLWHA was found in women with junior high school education. Based on the previous explanation, gender affects the level of resilience, as well as last education. Women have a lower level of resilience than men because of a lack of motivation to recover and tend to be more sensitive. Men tend to think positive

and optimistic about getting healthy because they feel they have a great responsibility towards the family, so they must be stronger. While women tend to feel useless when sick, that is what makes resilience low. In addition, those who have higher education will find out more information about their illness and find out how to maintain their health both physically and mentally.

Almost half of PLWHA who are following this study have an occupation as businessmen and housewife. The level of resilience when viewed from the normal level, they work as a businessman, and for a low level is a housewife that is three respondents (3%). Occupation is one of the factors that influence the economic rate in the family. Economics influences and plays a vital role in life. Income affects the economic situation of a family. The higher the income, the better the economic situation, while the lower-income is less (Rodliyah, 2017). It can assess the resilience of PLWHA by benchmarking the current occupation.

The majority of respondents were married (81%). Married respondents have a normal resilience rate of 45%. The previous study supports it, the factors supporting resilience also come from within the family. Family is the first and foremost place for individuals to be able to carry out their developmental tasks properly (Fikrie et al., 2021), including resilience. Interaction and exchange of attitudes in the family will affect resilience (Smith et al., 2008). Marital status has a role in changing resilient attitudes because excellent family support will have a good impact on the resilience of PLWHA.

Most respondents in the family are a father (44%) and mother (37%). Normal and high resilience is found in people living with HIV who act as fathers. Other research states that family support is a reinforcement for PLWHA to accept their status as PLWHA and continue to live productively. Family support is mainly manifested in the attention to health, reminding the consumption of antiretroviral drugs, and treating PLWHA when sick. In contrast, there are many ODHA do not get family support, because they have not opened their status to family members (Anggraeni & Wahyudi, 2018).

Respondents' background was identified to see psychological responses to problems that arise. Father is evident from the duties and obligations as the backbone of the family; indirectly, the burden of a father is huge. Father will feel stressed if he will sick and die because it will hamper the family economy if father as a person who earns money to support a family. Even mothers will feel the same impact. Mothers can be a person who earns money to support their family, but they also have to take care of all the family members. According to the explanation, mothers need higher resilience.

Almost all people living with HIV incorporated with "LSM" or supporting group for more than six months (97%), and they have normal to high resilience (94%). The previous study revealed that PLWHA, who get family support and environmental support or other PLWHA friends in the community, have a significant role to help PLWHA be able to adapt and deal with all their problem(s) (Anggraeni & Wahyudi, 2018).

Another study confirmed that PLWHA, who join the supporting group, could help them in their resilience process through exchanging ideas, sharing experiences/information with other PLWHA so their resilience can increase spontaneity (SPIRITIA, 2011). Previous study also showed that PLWHA who join supporting group will pass their HIV status to people who are trusted and provide support, and to the organization that help them (Kurniawan & Sulistyorini, 2019). It can be the way of PLWHA to share their feeling and to reduce their stress.

A social support group is a group of two or more people living with HIV getting together and supporting each other. Members who were incorporating are people with HIV and people who live with PLWHA or a combination. Initially, the group consisted of a combination of PLWHA with different backgrounds and the need to create a more specific group, such as a select PLWHA group, or with a specific background (transwomen, MSM, sex workers, or injecting drug user), or a combination of PLWHA and people living with PLWHA (SPIRITIA, 2011). In addition, the support given by friends and other supporting group members has a very positive impact on the survival of PLWHA in forming resilience.

The results showed that more than half the respondents' resilience was in the normal category (56%). In line with the previous study, 49.05% of respondents had average or normal resilience, 27.68% had high resilience, and 23.37% had low resilience (Araújo et al., 2017). Other research shows that resilience in people living with HIV can be seen from emotional awareness, emotional control, ability to control impulses, optimism, flexible and accurate thinking, empathy, relationships and achievement, and problem-solving skills (Hardiyani, 2015). The dynamics of the resilience of people living with HIV in emerging from the difficulties of their lives can be seen from the time needed to rise from adversity.

Three subjects make resilience arise, namely, from the aspects of "I am, I have, and I can". These aspects can overcome the pressures that occur in PLWHA life and become a better person (Ardana, 2018). Resilience can reduce the negative influence of life stress on physical, emotional, and functional or global well-being. Interventions that build personal capacity, coping skills, and social support can contribute to better management of HIV/AIDS and improve the quality of life (Fang et al., 2015).

The previous study states that the meaning of resilience in people living with HIV is "grateful" or "thanks to God". The three respondents in that study felt the God still loved them because God had given them temptation in the form of illness. They realized HIV as a punishment that must be accepted because of mistakes from their past. In addition, they also make HIV as an alarm so that they always remember not to do bad things. They get closer to God and their family. At present, they feel happier and become more independent (Audina, 2019).

The resilience of PLWHA in this study was mostly normal and high; only three respondents had low resilience because they had strong internal and external support. The difference between normal and high resilience can be distinguished from awareness in treatment. Viewed from PLWHA with normal resilience, respondents can rise from the problems faced. If the respondents are still not adhere to take ARV, then resilience is still unstable. For respondents with high resilience, they have a good status of that condition. They quickly recovered from the problem, and they were also very aware of not even dropping out in medication. Another factor is high optimism. Respondents believe that they can control their life in a better way. One example of optimism is that they believe everything happens can change for the better if they can accept it.

External factors that make respondents more resilient are family support and support from supporting group members. They said that by gathering with fellow PLWHA in SG, they became more grateful because they were still better than those who already had a severe illness and had even died. These assumptions make them more resilient and willing to rise from grief and want to continue to take medication, for longer life, because they know that their illness cannot be cured.

The questions in the Brief Resilience Scale questionnaire contained two types, namely favorable and unfavorable. In question items, 1,3,5 are favorable questions, while 2,4,6 are unfavorable questions. In the first question, the majority of respondents answered: "agree". For the questions in number two, the most answer is "disagree". The third question is mostly answered by "agree". The fourth question the majority of answers "disagree". The fifth question majority answered by "agree". Furthermore, the last question, the majority of respondents answered: "disagree". From the results of this study, it can be explained that the average respondent has a normal attitude of resilience.

All the questions on the Brief Resilience Scale questionnaire illustrate the characteristics of resilience in the perseverance indicator. Perseverance is a specific condition with a positive attitude and resilience in dealing with distress. It can be used as a strength to fight back in existing conditions and can be disciplined (Wagnild & Young, 1993).

According to the result that the median score of resilience is 25, with lowest score is 6 and highest score is 30, approaching maximum score of the BRS. It means that PLWHA who following SG have an impact on their resilience. The supporting group as prompt treatment for PLWHA can be categorized as secondary prevention for multilevel intervention management of HIV/AIDS, especially in Indonesia (Susanto et al., 2021). This activities of intervention has an impact toward their psychosocial aspect. The activities of group support can improve their resilience and mental health status.

This study also explained the resilience of PLWHA, with resilience, PLWHA can cope with the stress experienced in their future lives. If they have normal or high resilience, they will be better at managing stress. The results of this study can be used as a rehabilitative intervention by providing knowledge on how to increase good resilience. Sharing with fellow PLWHA through supporting group can also provide the best experience in increasing resilience. With the stress and resilient attitudes that occur in people living with HIV is expected to make a better person.

In addition, non-governmental-based supporting group organizational have positive impact toward resilience level among PLWHA. NGO-based supporting group can help government to reduce the illness and stress level among PLWHA and the last impact is to prevent death-related HIV AIDS, as the government target toward zero death related to HIV AIDS.

CONCLUSION

The resilience level of people living with HIV AIDS who are members of a supporting group in Jember, Indonesia show that the majority of respondents' resilience is in the normal to high category is 94% after they followed supporting group more than 6 month. NGO-based SG have an impact to PLWHA resilience level due to their psychosocial problems through its activities. The resilience level of PLWHA showed on normal to high category after they followed SG more than 6 month. The normal to high level of resilience manifest the role of SG. The results of this study are expected to be update information about resilience. Resilient will have a significant impact on health. Health providers can provide new PLWHA to join the supporting group or refers them to existing HIV AIDS supporting group. As an organization engaged in the field of HIV AIDS, supporting groups can maintain their support for PLWHA.

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