Association between Participation in HIV/AIDS Peer Group, Stigma, Discrimination, and Quality of Life of People Living with HIV/AIDS

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ABSTRACT

Background: The quality of life of people living with HIV/ AIDS (PLH) is of public health concern and calls for attention. The quality of life of PLH may be affected by stigma and discrimination. Peer group of PLHs may have an important role in improving the quality of life of PLHs. This study aimed to investigate the association between participation in HIV/ AIDS peer group, stigma, discrimination, and quality of life of PLHs.
Subjects and Method: This was an analytic and observational study with cross sectional design. This study was conducted in Tulungagung, East Java, from November, 2016 to January, 2017. A total of 65 PLHs participating in HIV/ AIDS peer group and 35 PLHs not participating in HIV/ AIDS peer group were selected by fixed exposure sampling. The dependent variable was quality of life of PLHs. The independent variables were participation in HIV/ AIDS peer group, stigma, and discrimination. The data were collected by a set of questionnaire and analyzed using path analysis model.
Results: Participation in HIV/ AIDS peer group (b=0.27; p<0.001), social support (b=0.43; p<0.001), and family support (b=0.18; p=0.021), had positive associations with a decrease in stigma and discrimination towards PLHs. Higher income (b=0.33; p=0.026), higher education level (b=0.21; p<0.001), less stigma and discrimination (b=0.33; p<0.001), had positive associations with quality of life of PLHs. Core self evaluation showed positive association with quality of life of PLHs (b=0.31; p<0.001).
Conclusion: Participation in HIV/ AIDS peer group, social support, and family support, are positively associated with a decrease in stigma and discrimination towards PLHs. Higher income, higher education, less stigma and discrimination, are positively associated with quality of life of PLHs. Core self evaluation is positively associated with quality of life of PLHs.

Keywords: HIV/ AIDS, peer group, stigma, discrimination, social support, quality of life

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BACKGROUND

HIV/AIDS becomes a current serious health problem for the world (WHO, 2015). AIDS is a series of diseases that emerge due to HIV virus, in which the body immune weaken (Bare and Smalter, 2005). The disease was firstly found in New York City in 1981, and it is estimated that it will cause the death of more 25 million people all over the world (Uvikacansera, 2010). In Asia alone, it was estimated in 2015 there were 3.5 million people who got infected with HIV (WHO, 2015). Since it was found for the first time back in 1987 the number of people who get infected with HIV is getting increasing. The cumulative number of HIV infection had been reported up to March 2016 and it reached 198,219 cases with the highest number of HIV infection was in DKI Jakarta (40.500) followed with East Java Province (26.052) and Papua (21.474).

Meanwhile the highest number of AIDS cases was in East Java Province (13.623) followed with Papua (13.328), DKI Jakarta (8.093).

The high number of HIV infection in East Java was in Surabaya, Malang Municipality, Banyuwangi, Jember, and Tulungagung. According to Tulungagung Health Office, the number of HIV/AIDS cases in Tulungagung from January up to December 2016 was 1,565. Most cases (479 kasus) were suffered by non professsional/ employee, 355 people were housewives, and 218 people were sex workers. The number had enlarged the monthly HIV/AIDS cases in Tulungagung Regency. PLH who died during the period of January up to December 2016 were about 69 people. In addition to accepting their status, PLH also has to receive stigma from the society that make them getting more afraid to reveal their status.

HIV/AIDS generates quite extensive problems onto infected individuals, both physically and psychologically. Discrimination stigma remains the main problem which is not yet properly overcome. Stigma may come from family, society as well as the persons. The problems illustration above indicates that aside from affecting physical welfare, HIV/AIDS also lead to disrupted quality of life. One's quality of life is an important component in evaluating PLH's welfare and life. Improvement on quality of life of PLH was one of the purposes of Strategic National Action Plan (SNAP) on AIDS countermeasure 2010-2014. The effort on improving PLH's quality of life in Indonesia has been conducted by various parties, however it is still fragmentary and extremely depends on regional condition (Komisi Penanggulangan HIV/AIDS, 2010).

Mona et al., (2015) stated discrimination turns to be a problem for PLH's quality of life however there are several factors that are not intended for reducing stigma instead making someone accept his/her status. According to Basavarat et al., (2010) there were previous studies that studied about the quality of life of people with HIV and they showed the association between various psychosocial, spiritual, symptomatology, and physical health factors.

According to the Regulation of Minister of Health No. 21/2013 on HIV/AIDS countermeasure, HIV/AIDS should obtain distinctive attention from preventive, promotive, curative and rehabilitative sides in order to reduce the morbidity and mortality rate and also to improve PLH's quality of life.

One of the efforts to improve quality of life of PLH is by conducting assistance, including peer support. Peer support is conducted by PLH to another PLH, especially PLH who newly discover their status (Yayasan Spiritia, 2011).

Life quality of PLH should obtain attention and be improved since the number of HIV/AIDS incidence is getting bigger each year. The previous studies in Indonesia are not yet able to particularly analyze the effect of Peer Support Group participants and non participants that affect PLH's quality of life that is affected by confounding factors.

SUBJECTS AND METHOD

The study used analytic observational with cross sectional approach. The study was conducted from November 2016 to January 2017 in Tulungagung Regency. The variables of the study were family support, social support, and discrimination stigma. The target population of the study was PLH in Tulunagung Regency. There were a total of 100 PLHs as the subjects of the study who were selected by using quota sampling and

exposure sampling. Data collection technique used was questionnaires. The data were analyzed by using path analysis.

RESULTS

1. Univariate analysis

Table 1 showed sample characteristics. Table 1 showed that as many as 54% study subjects were at age ≥35 years, 46% were married, 66% had education <Senior high school, and 51% had income ≥Regional Minimum Wage.

For social support there was a total of 45% who supported and 55% who did not support. For family support there was a total of 56% who supported and 44% who did not support. IN addition, the result of core self evolution obtained a total of 51% received excellent and 49% received poor core self evolution. A total of 55% of study subjects enjoyed excellent quality of life and 44% suffered from inferior quality of life.

Table 1. Sample Characteristics

Characteristics	Criteria	n	%
Age	< 20 years	1	1.0
	20-35 years	45	45.0
	≥35 years	54	54.0
Marital Status	Not married	26	26.0
	Divorced/widow/widower	28	28.0
	Married	46	46.0
Education	<Senior High School	66	66.0
	≥Senior High School	34	34.0
Occupation	Unemployed	16	16.0
	Employed	84	84.0
Family Income	< Regional Minimum Wage	49	49.0
	≥ Regional Minimum Wage	51	51.0
Peer Support Group	Participation	59	59%
	No Participation	41	41%
Discrimination Stigma	Getting Discrimination Stigma	51	51%
	Free from Discrimination Stigma	49	49%
Social Support	Strong	45	45%
	Weak	55	55%
Family Support	Strong	56	56%
	Weak	44	44%
Core self evolution	Excellent	51	51%
	Poor	49	49%
Quality of Life	Excellent	55	55%
	inferior	45	45%

2. Path analysis

The result of data analysis indicated that the value of degree of freedom (df)=11 it meant *over-identified* that *path analysis* is feasible to be carried out. Based on Table 3 of the study result:

Quality of life was affected by income, sore self evolution, and free from discrimination/stigma.

1) Each unit increase of income would increase quality of life by 0.33 unit (b=0.33; p<0.001).
2) Each unit increase of core self evolution would increase quality of life by 0.31 unit (b=0.31; p<0.001).
3) Each unit increase of free from discrimination/stigma would increase quality of life by 0.33 unit (b=0.3; p<0.001).

Free from discrimination/stigma was affected by social support, family support, and PSG participation.

1) Each unit increase of social support would increase the condition of being free from discrimination/stigma by 0.43 unit (b=0.43; p<0.001).
2) Each unit increase of family support would increase the condition of being free from discrimination/stigma by 0.18 unit (b=0.18; p<0.001).
3) Each unit increase of PSG participation would increase the condition of being free from discrimination/stigma by 0.27 unit (b=0.27; p<0.001).

Income was affected by education. Each unit increase of education would increase income by 0.21 unit (b=0.21; p<0.001).

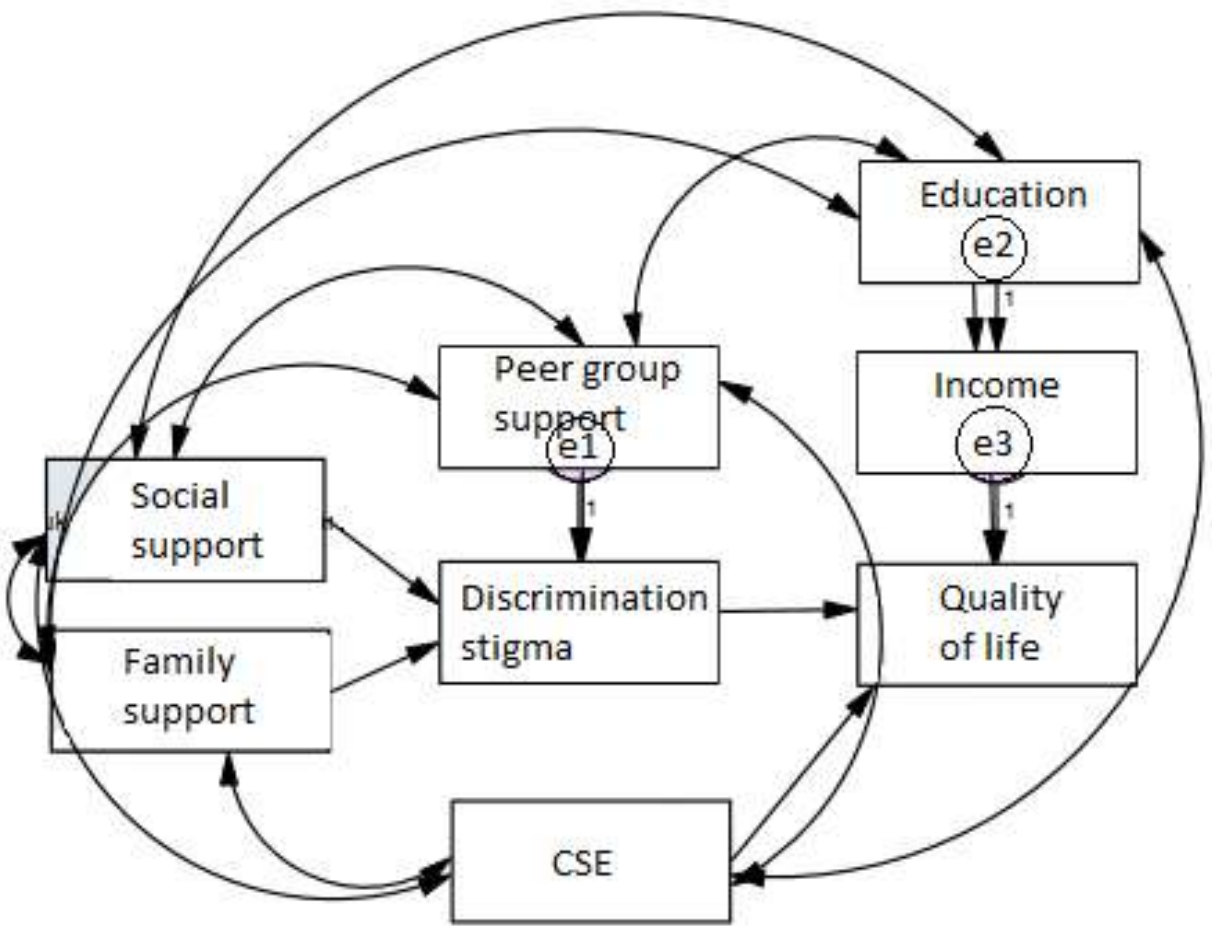

Figure 1. Structural Model of Path Analysis

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Table 3. The result of path analysis on association between PSG, discrimination stigma and PLHs' quality of life.

Dependent Variable		Independent Variables	b*	p	β**
Direct effect					
Quality of life	←	Income	0.33	0.026	0.77
Quality of life	←	Core self evolution	0.31	<0.001	0.71
Quality of life	←	Free discrimination/ Stigma	0.33	<0.001	2.41
Indirect effect					
Free discrimination/ Stigma	←	Social Support	0.43	<0.001	0.30
Free discrimination/ stigma	←	Family Support	0.18	0.021	0.13
Free discrimination stigma	←	Peer group support	0.27	<0.001	0.11
Income	←	Education	0.21	<0.001	4.69
Model Fit					
CMIN (X^2) = 15.39		p = 0.165 (> 0.05)			
CFI = 0.96		(≥0.90)			
NFI = 0.90		(≥0.90)			
GFI = 0.94		(≥0.90)			
RMSEA = 0.063		(≤ 0.05)			
*= Unstandardized path coefficient		**=standardized path coefficient			

DISCUSSION

1. The association between core self evolution and quality of life

There was a positive association between core self evolution and quality of life and it was statistically significant. PLHs who receive excellent core self evolution will have better quality of life and vice versa. Their acceptance on their status as PLH usually becomes problem in which they themselves cannot accept it yet. They consider themselves as being cursed by God by using the disease. Poor Core self evolution will worsen the quality of life. Core self evolution consists of four aspects namely locus of control, neuroticism, self efficacy and self esteem. According to Hiller dan Humbrick (2005) the division of core self evolution into 4 concepts in which each concept has value to change personality, thus it will affect one's quality of life. Personality change involves self efficacy that may change him/herself. There are a lot of factors that affect core self evolution, among others are education and income. Asgari (2013) elaborates that the effect of core self evolution toward self transformation and it affects one's quality of life (b= 0.31; p< 0.001).

2. The association between discrimination/stigma and quality of life

The result of the study indicated that there was a positive association and it was statistically significant by 0.33. PLHs who were free from discrimination were likely to have higher quality of life and vice versa, PLHs who receive stigma will increase the anxiety and depression rate and their self efficacy is getting lower thus affects the quality of life. Scientifically, PLHs who receive strong stigmatization, their body immune will be decreasing, since it is very vulnerable.

Zahro (2016) stated that PLHs who receives stigmatization, their quality of life will be worsened. In the theory, quality of life is subjectively affected by welfare, satisfaction and happiness. Welfare, happiness and satisfaction of PLHs who receive stigmatization will be decreasing. According to Rozi (2015) stigmatization on PLHs still remains a problem to be solved.

3. The association between peer group support and quality of life through discrimination/ stigma

The result of the study with Amos indicated that there was appositive association and it was significant between PSG participation

and the condition of free from discrimination/stigma. PLHs who actively participated in PSG had bigger possibility to be free from discrimination, compared to PLHs who did not participate in PSG (b=0.27; p=0.001). The result of the study showed that most PLHs participated in PSG activities, however there are some who are less active in participating that they did not join the activities held by PSG. Even though the activities held by PSG were considered truly advantageous for PLHs' survival, they could get knowledge and new friends who endure the same fate.

The statement is supported by a study conducted by Rozi et al., (2016) about the role of PSG to improve the quality of life of PLHs, it is considered truly helping in motivating and supporting PLHs for a better life, therefore excellent and regular PSG is greatly needed for PLHs' assistance. In addition, discrimination stigma is one of the factors that cause declining PLHs' quality of life it is because of society's lack of understanding that consider PLHs should be avoided. Zahro et al., (2015) stated that discrimination stigma remains main problem which is not yet solved well. Thus, it leads to PLHs' worse quality of life since they do not obtain encouragement and support to be better. They are becoming more cloistered about their status. The association uses the theory of quality of life that sees from subjective and objective aspects explains that with the PSG participation, quality of life may get improved. It can be spotted from happiness, life satisfaction, physical and psychological welfare. The study and the previous ones are in accordance with the theory that it improves happiness and welfare.

4. The association between family support and quality of life through discrimination/ stigma.

The result of the study indicated that there was a positive and significant association between family support and the condition of being free from discrimination. PLHs who obtained strong family support were likely to be more free from discrimination than those who obtained weak support (b= 0.18; p= 0.021). A study by Harefa (2012) explained that family support plays important role in the survival of PLHs. The result of the study indicated that most of PLHs obtained excellent categorized family support, therefore with the occurrence of strong family support it is able to improve the quality of life and the smaller possibility for discrimination.

The statement is supported by Friedman (2010) explain that family is the closest persons who share important element in life, since there are roles and functions of family members which are interrelated and interdependent in giving support, love, and attention harmoniously to achieve mutual purpose.

A study by Henny (2014) resulted r= 0.67 in which there was a positive family support with dysfunctional PLHs both psychologically and physically. Family is a shelter and haven for anyone including PLHs. PLHs should obtain more support and maximum attention for their survival.

The study is in line with the theory of quality of life explained by Ventergoth (2003), that factor that affects the quality of life of HIV/AIDS patients in particular is family support. According to Friedman (2010) the role of family support should be accountable by each family member, among others by accepting the family members for whatever the condition is.

5. The association between social support quality of life through discrimination/ stigma

The result of the study showed that there was a positive and significant association between social support and the condition of being free from discrimination. PLHs who obtained strong social support were likely to be more free from discrimination than those with weak support (b= 0.43; p < 0.001).

The study is supported by Latifa and Sunarti (2011) that social support may reduce stigmatization and discrimination toward PLHs. Support, no matter how small it is greatly affects PLHs' mindset. The study emphasized more on the role of civil society in reducing stigmatization and discrimination by conducting various actions, and setting out dialog to various sources and forums, so their opinion is audible toward a lot of people.

6. The Association between education and quality of life through income

There was a positive association between income and quality of life and it was statistically significant. PLHs with obtained high income had excellent quality of life (b= 0.27; p<0.001). A study by Nazir (2006) explained that quality of life is affected by education and income. Education functions as the beginning to get better income. The higher education of PLHs is, it is more likely to get high income so they are able to improve the quality of life.

PLHs truly need financial support since they think that the illness they suffer from is costly. And so, if their income is small it will affect the quality of life. It is supported by Kosim et al., (2015) that education and income are important matters in improving one's quality of life. The higher the education level is, the higher income and quality of life will be.

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