

FACTORS RELATED TO QUALITY OF LIFE AMONG PEOPLE LIVING WITH HIV IN INDONESIA: A CROSS-SECTIONAL STUDY

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ABSTRACT

People living with HIV (PLWH) have a complex problem with their disease including stigma and psychological problems. This research focused on measuring level of self-esteem, perceived human immunodeficiency virus (HIV) stigma, social support, and quality of life (QOL) among PLWH in Surabaya, Indonesia. Comparing part of social support which were by family and by friends would be explained. Our study used a cross-sectional correlation design. Variable self-esteem was measured using State Self-Esteem Scale by Heatherton and perceived HIV stigma by The Berger Scale, the social support was the multidimensional scale of social support by Zimet and WHOQOL-HIV instrument was by WHO. Univariate analyses and multiple regression analyses examine between predictors. The existence of moderate level of perceived HIV stigma was observed (mean: 95.67). There were significantly positive relationships between self-esteem and QOL ($p < .01$; $r = .642$); social support and QOL ($p < .01$; $r = .592$). In contrast, perceived HIV stigma showed a negative correlation with QOL ($p < .05$; $r = -.222$). In self-esteem ($p < .01$), social support by family ($p < .01$), and that by friends ($p < .01$) were shown to be significant predictors of higher QOL level. Self-esteem and support by family and friends were considered possible promoting factor of QOL of PLWH.

Keywords: HIV; PLWH; Stigma; Indonesia



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INTRODUCTION

The World Health Organization (WHO) estimated that by the end of 2022, 39.0 million people living with HIV (PLWH) and in 2022, 630,000 people died from HIV-related causes globally around the world. In Indonesia, cumulative people living with HIV and AIDS (PLWHA) till 2022 was estimated that 540,000 people (UNAIDS, 2023), while in end of 2019, Surabaya were approximately 915 new HIV cases where was the highest HIV and AIDS cases compared with any other city in East Java, Indonesia (Khairunisa et al., 2023).

A study in India explained that most PLWHA have low self-esteem, social support, and quality of life (Wani, 2020). mentioned that factors such as insurance and employment status, monthly income, age, being male, and educational level influence the quality of life of PLWHA in Iran (Kalan et al., 2019). In Indonesia, PLWHA are often stigmatized and obtain a low level of support from their family (Sitorus et al.,

2023). In Surabaya, PLWH mostly felt fear of death, feeling of guilt, and feeling no future (Citra et al., 2023).

Psychological factors could be influenced all of aspects of QOL among PLWH. The factors are needed to increase level of QOL. High level of QOL may be indicated high psychological health among PLWH. Nurses had a crucial role to identify level of QOL among PLWH at hospital or community. Knowing the factors and how the factors related to QOL among PLWH would be described in this research. On clinical field, the results of the research could be evidence based to improve the intervention increasing QOL among PLWH.

METHOD

Study design

This study employed a cross-sectional correlation design and descriptive analytics at a non-governmental organization

related to HIV and AIDS and a hospital in Surabaya in September 2018.

Setting and samples

The researcher investigated the total respondents needed using G*Power 3.1.9.2. software. The study planned to use multiple linier regression and bivariate analyses. Based on a medium effect size 0.15, α (alpha) error probability < 0.05, Power (1- β error probability) 0.80, and the number of predictors = 10, The total number of respondents needed in this study was 118 respondents with purposive sampling.

The inclusion criteria in this study were PLWH aged 18 years or older, fluent in Indonesian, and willing to give their informed consent. Exclusion criteria was participants who were on AIDS-infected.

Data collection

The demographic characteristics recorded in this study include age, gender, marital status, highest educational level, employment, length of HIV diagnosis, and severity level (stage 1 or 2). The self-esteem variable was measured using the State Self-Esteem Scale by Heatherton (Heatherton & Polivy, 1991) which consists of 20 items that measure positive and negative feelings about oneself. Higher scores indicate higher self-esteem. Next, the Berger Scale, consisting of 40 items, was used to measure the perceived HIV stigma variable (Berger et al., 2001). The scale was translated into Bahasa Indonesia (Nurdin, 2013) and a high score indicates greater stigma. Meanwhile, the Indonesian version of the multidimensional scale of social support (Zimet et al., 1988) was used to measure the social support variable. This scale comprises 12 questions, with four items, each addressing social support from family, friends, and special persons. Higher scores indicate higher social support.

The WHOQOL-HIV instrument (WHO, 2002) is specific to HIV and AIDS conditions. The instrument contains 31 items and has six domains: physical, psychological, level of independence, social relationship, environment, and spiritual/religious/personal beliefs.

Data analysis

Data analyses in this research were conducted using the Statistical Package for Social Sciences (SPSS) version 24.0.0.0 software and Excel spreadsheets. A mean or a percentage was calculated for the respondents' demographic status. Univariate analyses (descriptive analysis) were used to measure the level of each variable (self-esteem, perceived HIV stigma, social support, and QOL), and multivariate analyses (non-parametric test) were employed to examine overall perceived HIV stigma, self-esteem, social support, and QOL based on demographic characteristics. Additionally, Pearson correlation coefficients were used to predict the relationship between variables. The last analysis used multiple linear regression to find predictors influencing the level of QOL among PLWH.

Ethical considerations

The research was approved by the Epidemiologic Study and Ethics Committee of Airlangga University Hospital, Indonesia (No:123/KEH/2017). The participants provided their written, informed consent, and no identifying information (name, address, telephone number) was collected.

RESULT

The average age of the respondents was 36.03 years old and most graduated from high school (66 participants or 55.9%) (Table 1).

Table 1. Demographic data and HIV-related information (n = 118)

Variable	n (%)
Age (years)	36.03 ± 7.90
≤ 35	66 (55.9)
≥ 36	52 (44.1)
Gender	
Male	81 (68.6)
Female	37 (31.4)
Marital status	
Single	54 (45.8)
Married with stable partner	46 (39.0)
Divorced	18 (15.3)
Highest education level	
Primary school	11 (9.3)
Middle school	23 (19.5)
High school	66 (55.9)
College or University	18 (15.3)
Employment	
Unemployed	16 (13.6)
Employed	102 (86.4)
Length of living with HIV (months)	
≤ 48	76 (63.9)
≥ 49	42 (36.1)
Severity level	
Stage 1	114 (96.6)
Stage 2	4 (3.4)

The mean score for the self-esteem variable was 68.11 (the maximum possible score was 100). The perceived HIV

stigma variable obtained a mean score of 95.67, with the maximum possible score being 160 (Table 2).

Table 2. Level of self-esteem, perceived HIV stigma, social support and QOL

Variable	Range	Minimum	Maximum	Mean	Std. Dev.
Self-esteem	20-100	42	96	68.11	9.89
Perceived HIV stigma	40- 160	51	148	95.67	17.20
Social Support	12 – 84	30	84	59.47	12.99
QOL	31- 155	69	154	103.05	16.47

The results revealed that age, employment status, severity level, gender, and marital status did not influence self-esteem, perceived HIV stigma, social support, and QOL among PLWH. Moreover, respondents with college degrees had significantly higher mean self-esteem (71.78; $p < .05$),

social support (67; $p < .01$), and QOL (115.83; $p < .01$) than respondents with primary school, middle school, or high school education. The results also showed that perceived HIV stigma is not associated with last education (Table 3).

Table 3. Self-esteem, perceived HIV stigma, social support, and QOL by highest education level

Variable	Total	Primary school	Middle school	High school	College	P value
	Mean (Std. Dev)	Mean (Std. Dev)	Mean (Std. Dev)	Mean (Std. Dev)	Mean (Std. Dev)	
Self-Esteem	68.11 (9.89)	64.82 (4.89)	63.91 (9.45)	69.12 (9.87)	71.78 (11.04)	0.018*
Perceived HIV Stigma	95.67 (17.2)	95.36 (12.87)	97.74 (18.50)	95.26 (18.61)	94.72 (12.79)	0.671
Social Support	59.47 (12.99)	41.73 (4.69)	52.74 (13.12)	62.71 (11.33)	67 (8.32)	0.000**
Quality of Life	103.05 (16.47)	89.64 (7.82)	97.96 (13.22)	103.58 (16.22)	115.83 (16.5)	0.000**

* $p < 0.05$ ** $p < 0.01$ **non-parametric test: Kruskal-Wallis

The respondents who have lived with HIV for less than 48 months had significantly higher mean social support (62.48;

$p < .01$) and QOL (105.09; $p < .05$) than those who have lived with HIV for more than 49 months (Table 4).

Table 4. Self-esteem, perceived HIV stigma, social support, and QOL by length of living with HIV (month)

Variable	Total	48 months or less	More than 49 months	P value
	Mean (Std. Dev)	Mean (Std. Dev)	Mean (Std. Dev)	
Self-Esteem	68.11 (9.89)	67.94 (10.22)	68.44 (9.34)	0.810
Perceived HIV Stigma	95.67 (17.2)	97.74 (17.68)	91.78 (15.73)	0.062
Social Support	59.47 (12.99)	62.48 (11.73)	53.80 (13.50)	0.002**
Quality of Life	103.05 (16.47)	105.09 (15.23)	99.22 (18.12)	0.023*

Additionally, there was a significantly relationship between self-esteem ($r = 0.642$; $p < 0.0001$), perceived HIV stigma ($r = -0.222$; $p < 0.016$), social support ($r = 0.592$; $p < 0.0001$), with QOL (Table 5).

self-image, and public attitude about PLWH. The positively significant correlation as a predictor of QOL in PLWH was the highest education level ($p < 0.000$), and the negatively significant correlation was negative self-image ($p < 0.003$), with an R^2 of 0.228.

Table 5. Correlation between self-esteem, perceived HIV stigma, social support and QOL

Variables	QOL	P value
Self-esteem	0.642	0.0001
Perceived HIV stigma	-0.222	0.016
Social support	0.592	0.0001

Factors related to QOL

The regression analysis started with analyzing the following socio-demographic factors: age, last education, employment status, duration of living with HIV, severity level, gender, and marital status. The results showed that only the highest education factor was found to significantly correlate with the quality of life ($p < 0.000$) (Table 4), with an R^2 of 0.165.

Next, the following three factors were investigated: demographic factors, perceived HIV stigma, and self-esteem. The R^2 of these three factors was 0.703. The self-esteem factor did not have a sub-domain. The results showed that the highest education level ($p < 0.001$) and self-esteem ($p < 0.000$) were positively significant predictors of QOL in PLWH. Meanwhile, the duration of living with HIV ($p < 0.049$) was negatively significant as a predictor influencing QOL among PLWH. Next, negative self-image was not significant in this step.

The second step added the sub-domains of perceived HIV stigma, namely age, last education, employment status, duration of living with HIV, severity level, gender, marital status, personalized stigma, disclosure concern, negative

In the fourth step, social support by family, friends, and special persons was added to the regression analysis. As predictors of quality of life, self-esteem ($p < 0.000$), social support from family ($p < 0.000$), and social support from friends ($p < 0.009$) were positively significant. The highest education level was not significant, and the R^2 for this step was 0.744.

Table 6. Linear regression analysis for QOL

Predictors	Step 1		Step 2		Step 3		Step 4	
	B	p-value	B	p-value	B	p-value	B	p-value
Demographic factors								
Age	.033	.700	.020	.812	-.062	.402	-.080	.219
Highest education level	.406	.0001 ^b	.391	.0001 ^b	.232	.001 ^b	.110	.133
Employment	-.027	.750	.007	.935	-.012	.853	-.032	.619
Length of living with HIV	-.089	.305	-.142	.097	-.136	.049 ^a	-.074	.265
Severity level	.107	.208	.106	.197	.053	.439	.062	.340
Gender	.015	.865	.047	.568	-.028	.675	-.051	.424
Marital status	-.004	.963	.000	.997	.022	.752	-.045	.487
Perceived HIV stigma								
Personalized stigma			-.095	.521	-.008	.914	.064	.375
Disclosure			.173	.108	.018	.790	.045	.506
Negative self-image			-.251	.003 ^b	-.029	.700	.021	.764
Public attitude			.170	.294	.040	.591	.093	.192
Self-esteem								
					.588	.0001 ^b	.777	.0001 ^b
Social support								
By family							.909	.0001 ^b
By friends							.698	.009 ^b
By special person							.070	.488
R ²	.165		.228		.703		.744	
F	22.912		16.938		37.199		47.189	

Note. a. $p < .05$ b. $p < .01$

Step 1: Sub-domains of demographic factors related to QOL

Step 2: Sub-domains Demographic factors and perceived HIV stigma (sub-domains) related to QOL

Step 3: Sub-domains Demographic factors, perceived HIV stigma, and self-esteem related to QOL

Step 4: Sub-domains Demographic factors, perceived HIV stigma, self-esteem, and social support related to QOL

DISCUSSION

The factors that might impact to the higher self-esteem was the last education. Higher education can be as high predictor to improve level of self-esteem. The result was linier with research which presented by Setyoadi (Setyoadi et al., 2018). The research explained that level self-esteem among PLWH in Malang, Indonesia had a high level.

Our study observed that the perceived HIV stigma among PLWH is at a moderate level. This finding is important because, to our knowledge, no previous studies have mentioned this in Indonesia. Previous research from Ethiopia explained that the level of perceived HIV stigma among PLWHA in Western Ethiopia was high due to poor social support (Turi et al., 2021). Ataro et al (2020) also mentioned that in Ethiopia, gender is related to perceived HIV stigma (Ataro et al., 2020). Moreover, Li & Sheng (2014) found that in Henan, China, PLWH experienced a moderate level of perceived HIV stigma, where the women had a higher level of disclosure stigma than men (Li & Sheng, 2014). The results reported that women had high-level of disclosure stigma than men. Some previous studies also explained high-level of perceived HIV stigma (Adane et al., 2020; Chekole & Tarekgn, 2021; Subedi et al., 2019).

Next, this study investigated the role of social support. The results revealed that the highest education level and duration of living with HIV were predictors of the background factors that increased the level of social support. Additionally, our study showed a strong correlation between self-esteem and social support. Previous literature has also mentioned the correlation between the highest education level and social support (Shamshad et al., 2023) (Abrefa-Gyan et al., 2016). as well as how the duration of the illness also contributed to the respondents' level of social support (Wani, 2020).

In this study, the respondents' quality of life varied. Studies have shown that the highest education level and duration of

living with HIV are associated with quality of life (Karkashadze et al., 2017). The results in this study indicate that PLWH who have higher education levels obtained a high level of quality of life. This result aligns with a previous study in Iran, which mentioned that educational level influenced the low level of quality of life among PLWHA (Maleki et al., 2020).

Self-esteem and social support have a positively significant relationship with the quality of life of PLWH (Sofro & Hidayanti, 2019). (Evi et al., 2015) also noted that social support, functional status, and general health perception are strong predictors of influence on women living with HIV in an urban area in Indonesia. Social support from family and colleagues or the community also significantly affects the quality of life of PLWH (Safitri, 2020). In India, (Chandrakanth et al, 2017) and (Manhas, 2014). mentioned a similar result where self-esteem positively affects quality of life.

Meanwhile, perceived HIV stigma has no significant relationship with the quality of life of PLWH (Van Der Kooij et al., 2021). In this study, the factors of self-esteem, social support from family, and social support from friends were used to predict the quality of life of PLWH by stepwise regression (step 4). The results show that the paradigm of thinking among PLWH in Indonesia has changed. The researcher assumes that PLWH and family members have built their trust with one another. Previous research also reported that close family and friends could have a great impact and provide fundamental support to people with HIV/AIDS (Arias-Colmenero et al., 2020). In Indonesia, wive was as a great support to husband who have HIV (Agnes et al., 2022).

IMPLICATION AND LIMITATIONS

The limitation of this study was that respondents who were invited to fill in the questionnaire could not come to the location. Therefore, the researcher actively communicated

with them to complete the questionnaire remotely. For clinical implications, this research will provide new knowledge to nurses who work at HIV and AIDS wards at hospitals or community health centers and for non-government organization staff to treat PLWH physically and psychologically to increase their quality of life. psychological intervention such as including family and friends as the best support to increase QOL among PLWH.

CONCLUSION

The moderate level of perceived HIV stigma observed in this study could not be overlooked. There were significant correlations between self-esteem, perceived HIV stigma, social support, and quality of life. Self-esteem, social support from family, and social support from friends can determine the quality of life of PLWH. Future research should focus on planning interventions and effective actions to reduce HIV stigma and increase the self-esteem of PLWH.

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AUTHOR CONTRIBUTION

ANS and PUR contributed to writing the manuscript. ANS contributed to the study's design and data analyses. The manuscript was revised by PUR. All authors have no conflict of interest and approved the manuscript.

CONFLICT OF INTEREST

The researcher describes that there is no conflict of interest in this study.

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