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## **HIV Disclosure and Quality of Life in People Living with HIV/AIDS in Yogyakarta**

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### **Abstract**

**Background:** Victory Plus Foundation is a Non-Government Organization that helps the population directly affected by HIV/AIDS in Yogyakarta. Status disclosure's research on People Living with HIV/AIDS (PLWHA) in Victory Plus Foundation is scarce. Even though the status disclosure is one of HIV spreading prevention, it has two-sided effects, both negative and positive, so its result can affect the quality of life despite PLWHA having tried to find a support system. Therefore, it is essential to know how the quality of life of PLWHA has opened up their status.

**Objective:** This study aimed to determine the relationship between HIV status disclosure and the quality of life of PLWHA in the Victory Plus Foundation, Yogyakarta.

**Method:** This descriptive-analytic correlation study with a cross-sectional approach was conducted in June-July 2019 on 68 PLWHA at the Victory Plus Foundation. Purposively, samples were asked to fill out a disclosure questionnaire and WHOQOL-BREF. Univariate data presented in descriptions and Chi-Square tested bivariate data.

**Result:** Most of the HIV status disclosure of PLWHA in the Victory Plus foundation was classified into a moderate category (77.9%) and low quality of life (64 %). The bivariate test result found a significant relationship between the HIV status disclosures with the quality of life in general ( $p = 0.001$ ) with a moderate relationship closeness ( $r=0.403$ ).

**Conclusion:** Consequently, there is a relationship between the HIV status disclosures with the quality of life of PLWHA in the Victory Plus Foundation in Yogyakarta.

**Keywords:** PLWHA, Disclosure, Status, HIV, Quality of Life

### **INTRODUCTION**

A relatively recent but rapidly growing in some key populations is a new description of the current Indonesia HIV epidemic. The number of HIV-infected individuals increased by at least three-fold between 2009 and 2014, based on the Indonesian AIDS Commission (Rahmalia et al., 2015). Among AIDS prevention programs, the recommendations relating to HIV status disclosure hold a crucial place beside other strategies for preventing HIV transmission (Yaya et al., 2015).

Disclosure of HIV status is an HIV patient's decision to reveal their personal information related to the illness they experienced to others (Evangelii & Wroe, 2017). When someone is infected with HIV, they have to consider several matters, such as death or the decision to inform others, whether friend, colleagues, family and most importantly, their sexual partners, of their illness (Minson, 2014).

Based on the meta-analysis results, it was found that status disclosure was mostly carried out by People Living With HIV/AIDS (PLWHA), especially with their sexual partners than other people such as family, friends, priests/imam, and colleagues (Adeoye-Agboola, Evans, Hewson, & Pappas, 2016). Things that influence PLWHA undisclosing their status was fear of stigma and the possibility of being excluded from social life (Adeoye-Agboola et al., 2016).

The seropositive HIV status disclosure has two opposite effects. On the one hand, the HIV status disclosure can motivate sexual partners to undergo Voluntary Counseling and Test (VCT), reduce risky behavior, and increase support to abide ART (Anti-Retroviral Therapy) treatment. On the other hand, the seropositive HIV status disclosure caused the HIV/AIDS patients to experience various unpleasant matters such as blame, discrimination, rejection, depression, loss of economic support and familial relationship disintegration (Atuyambe et al., 2014; Larkins, Reback, Shoptaw, & Veniegas, 2005; Stirratt et al., 2006). The seropositive HIV status disclosures also prompt anxiety in patients because they cannot predict the feelings, thoughts, and reactions of the people in their environment regarding their status (Liamputtong & Haritavorn, 2016). All of those effects indicate that HIV/AIDS can affect the PLWHA's quality of life.

Quality of life (QoL) is an essential component in evaluating the welfare of PLWHA. PLWHA must get special attention from a preventive, promotive, curative, and rehabilitative perspective to reduce morbidity and mortality and improve the QoL of PLWHA. The quality of life of PLWHA must receive attention and must be improved because HIV / AIDS incidence is increasing every year (Kurniasari, Murti & Demartoto, 2016).

The PLWHA's quality of life is influenced by many factors, both external and internal. Along with the development of HIV in the body, PLWHA will often face physical, psychosocial, psychological, and mental problems, both directly and indirectly, which will impact the quality of life of PLWHA (Rina, 2013). Based on previous research on the quality of life of PLWHA and the disclosure of

PLWHA status, it was found that PLWHA in Yogyakarta had a mediocre quality of life (53.95%) and had high disclosure of status to sexual partners (79.4%) (Farillahsari & Yasin, 2014; Rukmi & Darussalam, 2018). However, research on the disclosure of status to non-sexual partners such as the nuclear family, extended family, close friends, work colleagues, the community's environment, and its relation to the quality of life at the Victory Plus Foundation have not been explored further. Despite that, disclosing their HIV status to others like partners, family, and friends is essential to reduce the incidence of HIV infection and improve HIV treatment and care (Xu et al., 2017).

This research intended to identify the relationship between the HIV disclosure status and their quality of life among PLWHA at the Victory Plus Yogyakarta Foundation. The benefit of this research is strengthening theoretical support related to the development of HIV / AIDS research, where research on this topic is still rare. This study could become a reference for further actions regarding PLWHA holistically, both from a medical and psychosocial perspective by the family, government and society so that the quality of life of PLWHA will be improved.

#### **METHOD**

This research was a quantitative study with a descriptive correlational analytic method and a cross-sectional approach. The research was conducted in June - July 2019 at the Victory Plus Yogyakarta Foundation. A total of 68 PLWHA were taken by purposive sampling with inclusion criteria aged > 18 years, can read and write and have opened their status.

Data were collected using two questionnaires. The first questionnaire contains 20 questions about status disclosure consisting of 19 questions about adoption from a previous study (Leung, 2002) and one additional question regarding whom PLWHA has opened their status to. After being tested for validity, seven items failed and 13 questions were left with the validity test result showed  $r$  count of > 0.514 and the alpha Cronbach reliability test was 0.862. The questionnaire used Likert scale with a "strongly disagree" range (1) to "strongly agree" (5). The category of the disclosure of the status then calculated using the ideal mean and standard

deviation formula so that the range of values for low disclosure was <30.3, moderate was 30.3-47.6, and high was > 47.6.

The second questionnaire was the Indonesian WHOQOL-BREF to measure the quality of life of PLWHA, which was adopted from previous research (Kusuma, 2016). The second questionnaire has been tested for its validity and reliability (Ch Salim, Sudharma, Kusumaratna, & Hidayat, 2007), so it was not retested. With the standard transformation set by WHO, the QOL score was then categorized as low (score<79) and high (score≥80). Data analysis was performed by univariate and bivariate analysis. The Univariate data analyzed using frequency distribution and percentage, while the bivariate used the chi-square test.

This research has received permission from the General Achmad Yani University of Yogyakarta and the Victory Plus Foundation Yogyakarta. It also has passed the ethical clearance from General Achmad Yani University of Yogyakarta with ethical number SKEP / 088 / KEPK / VI / 2019.

**RESULTS**

Table 1 shows the average age of the respondents is 34.22 ± 9.28 years, most of them are male (72.1%), have private occupation (42.6%), single (64.7%), Muslims (85.3%), have senior high school education backgrounds (66.2%), live with their family (58.8%), and all undergo ARV therapy (100.0%).

The results of overview regarding the status disclosure and quality of life can be seen in Table 1, where most of the respondents have moderate disclosure (77.9%) and have a low quality of life (64.7%).

The bivariate test results are presented in Table 2, where the Chi-Square test results for disclosure of status and quality of life in general, found a significant relationship (p=.001) with a moderate relationship closeness (r=.403). For the physical (p=.01), psychological (p=.004), social (p=.001), and environmental (p=.008) domains, it was also found that there was a significant relationship with a low level of closeness except for the social

domain which was categorized in moderate closeness range (r=.416).

**Table 1. Respondent’s Characteristics Among PLWHA in Victory Plus Foundation Yogyakarta**

Characteristic	f(n)	%	Mean ± SD
<b>Age</b>	68	100	34.22 ± 9.28
<b>Gender</b>			
Male	49	72.15	
Female	19	27.9	
<b>Occupation</b>			
Unemployed	20	29.4	
Private employee	29	42.6	
Student	3	4.4	
Staff officer	6	8.8	
Everyday worker	6	8.8	
Housewives	4	5.9	
<b>Marriage Status</b>			
Married	16	23.5	
Never Married	44	64.7	
Widow	5	7.4	
Widowed	3	4.4	
<b>Religion</b>			
Christian	5	7.4	
Catholic	1	1.5	
Hinduism	3	4.4	
Buddhism	1	1.5	
Islam	58	85.3	
<b>Education Background</b>			
Illiterate	5	7.4	
Elementary School	3	4.4	
Junior High School	45	66.2	
Senior High School	14	20.6	
Academic/University			
<b>Living with</b>			
Family	40	58.8	
Relatives	3	4.4	
Friends	9	13.2	
Alone	16	23.5	
<b>Antiretroviral Therapy</b>			
Yes	68	100	
No	0	0	
<b>HIV Disclosure</b>			
High	9	13.2	
Moderate	53	77.9	
Low	6	8.8	
<b>Quality of Life</b>			
High	44	64.7	
Low	24	35.3	

**Table 2. Bivariate Analysis of HIV Disclosure and Quality of Life Among PLWHA in Victory Plus Foundation**

Domain	HIV Disclosure	QOL						Pv	Coef.
		Low		High		Total			
		n	%	n	%	n	%		
General	High	1	1.5	8	11.8	9	13.2	0.001	0.403
	Moderate	39	57.4	14	20.6	53	77.9		
	Low	4	5.9	2	2.9	6	8.8		
	Total	44	64.7	24	35.3	68	100		
Physical	High	5	7.4	4	5.9	9	13.2	0.010	0.345
	Moderate	48	70.6	5	7.4	53	77.9		
	Low	6	8.8	0	0.0	6	8.8		
	Total	59	86.8	9	13.2	68	100		
Psychological	High	4	5.9	5	7.4	9	13.2	0.004	0.372
	Moderate	46	67.6	7	10.3	53	77.9		
	Low	6	8.8	0	0	6	8.8		
	Total	56	82.4	12	17.6	68	100		
Social	High	3	4.4	6	8.8	9	13.2	0.001	0.416
	Moderate	45	66.2	9	11.8	53	77.9		
	Low	6	8.8	0	0	6	8.8		
	Total	54	79.4	14	20.6	68	100		
Environment	High	4	5.9	5	7.4	9	13.2	0.008	0.353
	Moderate	45	66.2	6	11.8	53	77.9		
	Low	6	8.8	0	0	6	8.8		
	Total	55	80.9	13	19.1	68	100		

## DISCUSSION

The results of the data analysis showed a relationship between the disclosure of HIV status and the general quality of life in PLWHA in a moderate closeness ( $r=0.403$ ) (Table 2). Most PLWHA in this research has moderate status disclosure (77.9%) and has a low quality of life (64.7%). These results are in line with Rwanda's research, which stated that the lack of disclosure of status is associated with poor physical and mental conditions in PLWHA (Biraguma, Mutimura, & Frantz, 2018). Meanwhile, other studies in Tanzania and Thailand show that disclosure of status is strongly associated with improving the quality of life of PLWHA patients (Bulali, Kibusi, & Mpondo, 2018; Bunjoungmanee, Chunloy, Tangsathapornpong, Khawcharoenporn, & Apisarnthanarak, 2014). Somewhat a different research results were obtained in America, which stated that disclosure of status would decrease with age and there is no significant difference from the quality of life of PLWHA before and after they disclose their status to others (Butler et al., 2009).

The disclosure of status is indeed a complex issue like a double-edged sword for PLWHA, producing positive or adverse effects. One positive example

of disclosure of status that can increase life quality is research conducted in China. This study stated that HIV patients usually (81.3%) revealed their HIV seropositive status to the family before receiving ART and it increase to 96.7% at the 24-month mark (Xu et al., 2017). Among those who disclosed their status to their family, they stated that most of them were satisfied with their decision because they got the support of their family, which increased from 90.4% at baseline, 91.8% at six months, 95.5% in a year, and 94.3% at 24 months. Most patients also received encouragement from their family in term of psychological, financial, and physical support and it increased significantly in 24 months (55.2% vs. 84.5%)(Xu et al., 2017). Evidence also showed a relationship between status disclosure and social support, where individuals who receive social support will have more self-esteem, better coping and a healthier lifestyle (Biraguma et al., 2018). The individual could avoid the anxieties of hiding their HIV seropositive status, thus lowering their stress and lowering risky behaviors (Mkize, 2009).

However, there are also some examples of adverse outcomes from the disclosure of status that will reduce the quality of life of PLWHA. For

example, PLWHA in Nigeria disclosed their status to at least one person within their social networks because the stigma was still the biggest obstacle for them. PLWHA in Nigeria was found to experience a lot of stigma and discrimination, such as rejection by the religious community in the form of accusations of infidelity, violations of trust and the assumption that these conditions are a punishment from God (Adeoye-Agboola et al., 2016). One qualitative study in India stated that most participants revealed HIV status to their sexual partners because the partners also had HIV, but they were afraid to open up to family, children or friends (Lakshmi, 2017). They felt that they had bad experiences related to their HIV status, such as difficulty getting sufficient food and unable to work to earn money like before being diagnosed with HIV. They also get stigmatized by health workers when they are sick (Lakshmi, 2017). These study results seem to underline that the fear of stigma and exclusion related to the disclosure of status of PLWHA.

Stigmatization of HIV in Yogyakarta is still high (Mawarni, 2017), and this stigma is not only obtained from the community but also from health workers (Hati, Shaluhiah, & Suryoputro, 2017; Maharani, 2014; Shaluhiah, Musthofa, & Widjanarko, 2015). The results of mentioned studies support the results of this study. The high stigma in Yogyakarta could be one of the reasons for the relationship between HIV status disclosure and the quality of life of PLWHA in Yogyakarta, where the disclosure of status in PLWHA is mostly in the moderate category, but the quality of life is mostly in the low category.

The relationship between HIV status disclosure and quality of life in this research is not only seen from general QoL but also seen through 4 other domains: physical, psychological, social and environmental domain.

Based on the p-value and closeness, the physical domain has the lowest p-value and closeness among the other domains (Table 2). Most PLWHA with moderate openness (77.9%) had a low quality of life in the physical domain (70.6%) (Table 2). It is consistent with Indonesia's research (Handayani, Ratnasari, Husna, Marni, & Susanto,

2019). However, it is somewhat different from the results of two studies conducted in South Africa, where the physical domain is in the third and fifth-lowest positions in the quality of life domain (Cronje, Williams, Steenkamp, Venter, & Elkonin, 2017; Tesemma, Abate, Abebo, & Madebo, 2019). The higher PLWHA disclosure gets, the more opportunity the PLWHA get to do more physical activities akin to ordinary people. Disclose HIV status can facilitate HIV care access and mobilize existing support networks (Fifield et al., 2015). Disclosing HIV status to others like sexual partners, family and friends is vital in decreasing HIV infection incidence and improving HIV treatment and health care (Xu et al., 2017). By adhering to ART treatment, the health of PLWHA will also improve, so that the ability to do physical activity will also increase.

However, in this study, the physical domain's quality of life was mostly in the low category (Table 2). PLWHA in this research could have difficulty to perform some daily physical activities while managing their illness. It is per with the research result which stated that PLWHA was challenged to attend their daily living tasks, participate in high physical activities, or have sufficient energy or vitality to engage in an active social life while managing HIV/AIDS (Basavaraj, Navya, & Rashmi, 2010). Pain, fatigue, poor nutrition, lack of rest and low CD4 cells are associated with physical limitations and disabilities from PLWHA (Basavaraj et al., 2010; Cronje et al., 2017; Handayani et al., 2019; Tesemma et al., 2019). PLWHA who have CD4 above 500 and normal nutritional status have QOL of 1.96 and 2.66 compared to their counterparts (Tesemma et al., 2019).

The second-lowest outcome of the quality-of-life domain based on status disclosure is the environmental domain ( $p = .008$ ;  $r = .353$ ) (Table 2). This research differ from research in North Africa, where the environmental domain is the highest (Tesemma et al., 2019). Openness can have a good impact on the environment; health care service is one example. High honesty of PLWHA will provide accurate information about their symptoms and conditions, making it easier to provide health care services. Maximum health

care services for PLWHA will raise patient satisfaction and has an impact on improving the quality of life of PLWHA (Mkize, 2009). However, the opposite will happen if PLWHA is not open to their disease.

The other issues related to the environmental domain are work and income issues. PLWHA should be able to adapt their life to their chronic diseases like the ability to work and employment status. Working PLWHA sometimes experiences difficulties due to several reasons like fatigue, routine medical appointment, medication, episodic illness, physical and cognitive limitations and side effects of ART (Basavaraj et al., 2010). PLWHA who disclosed their status, said they had difficulty getting a job and often felt tired due to ART's effects (Lakshmi, 2017).

Most PLWHA in this study worked in the private sector (42.6%) and did not work (29.4%). It could be one cause of the low quality of life in the environmental domain because people who do not have a job are prone to experience depression, anxiety, isolation, and low self-esteem (Basavaraj et al., 2010). PLWHA with depression 9.4 times will have an impaired QOL, and social isolation will make PLWHA 6 times have a worse QOL (Tesemma et al., 2019).

The third lowest domain in this study is the psychological domain ( $p=.004$ ;  $r=.372$ ). These results are consistent with previous research in Indonesia and South Africa (Cronje et al., 2017; Handayani et al., 2019). Based on the previous study, status disclosure decreased the adverse effects of the status hiding may induce, including anxiety and depression (Mkize, 2009). Disclosure of a positive HIV diagnosis can also reduce stress and improve psychological health (Deribe, Woldemichael, Wondafrash, Haile, & Amberbir, 2008). Openness of the PLWHA can encourage behavior in seeking appropriate medical treatment and gain social support to help them reach a better deal and cope with the implications of living with HIV (Mkize, 2009).

However, the result showed that 66.7% of the 77.9% PLWHA with moderate status disclosure had a low quality of life. The low quality of life of PLWHA in the psychological domain could have happened since this study did not dig deeper into

possible conditions that could reduce the QOL in psychological domain, such as stigma, health status, depression score, or nutritional status. PLWHA could have a variety of problems that worsen their psychological condition apart from depression such as ineffective coping, lack of social support, stigma, HIV-related work problems, body image problems, negative feelings, low self-esteem, and reduced ability to think, learn, memory and concentration (Biraguma et al., 2018; Cronje et al., 2017).

The highest scored domain in this study is the social domain ( $p=.001$ ;  $r=.416$ ). Previous research showed that the social domain occupied the highest score of all quality of life domains in PLWHA (Cronje et al., 2017; Handayani et al., 2019). This result is different from the results obtained in Nigeria, which found the social domain as the lowest one (Akinboro et al., 2014). Disclosure in PLWHA could improve their social domain in the quality of life. The more open the PLWHA gets, the more positive impact they can get in terms of the personal or social relation of the PLWHA. The reason behind this is because the PLWHA who reveal themselves well and correctly, in addition to giving detailed information to others, can lead others to understand the condition of PLWHA and offer their support. The support provided by others helps the PLWHA be more confident in interacting with others. Other positive effects of revealing a positive HIV status were the decrease in social isolation and an increase in social support (Mkize, 2009). It is possible for PLWHA to seek information and care for their medical, social and mental health services (Mkize, 2009).

The study result indicated that out of 77.9% of PLWHA with moderate disclosure, most of them have a low quality of life in the social domain (66.2%) (Table 2). The low QoL in the social domain could be caused by PLWHA's age. The average age of PLWHA in this study was  $34.22 \pm 9.28$  years and according to Pieter and Lubis, the early adulthood stage, i.e., at 31 - 40 years of age, are respecting as the time to get a new social life like a role as a husband or wife, parents, worker, or breadwinner (Handayani et al., 2019) and this is certainly not easy when someone is infected with HIV. Another thing that can exacerbate the social domain is a

lack of social support and high stigma. Based on previous research, people with good social support will have a better QoL of 6.18 than those who lack social support. Likewise, stigmatized people will have a QoL of 2.75 lower than those who are not stigmatized (Tesemma et al., 2019).

Although the QoL in this domain is mostly low, the social domain has the highest PV value and closeness with status disclosure. It could be the case since the PLWHA in this study is under the same institution, namely the Victory Plus Foundation. Hanging out with the same fated could improve the social domain because they could open up, support each other and get information and psychosocial services. It is consistent with previous research, which stated that disclosure of status has always been an essential factor in HIV prevention programs. Factors that could increase openness in PLWHA were general factors associated with the quality of life, such as living amongst friends and relatives, good social support, access to psychosocial services, and suitable financial condition (Zaidi et al., 2012).

#### **CONCLUSION**

The HIV status disclosure of PLWHA has a significant relationship with the general quality of life and quality of life in physical, psychological, social, and environmental domains. Most of the HIV status disclosure for PLWHA in Victory Plus is in the moderate category (77.9%) and has a low quality of life (64%). The low quality of life of PLWHA that disclose their status in this study requires further follow-up from policymakers, health workers and PLWHA. Policies are needed to help increase the disclosure of status to PLWHA, such as education regarding the stigma of PLWHA in the general public, counseling training for health workers and health promotion related to the prevention of HIV containing elements of HIV status disclosure. It is hoped that health workers will further improve their ability to conduct advocacy and will approach at-risk populations so that they are willing to conduct voluntary and counseling tests (VCT). PLWHA, who still have low-status disclosures or low quality of life, can be more active in joining the support or peer community to improve their quality of life.

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