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Factors Associated With Quality Of Life People Living With Hiv/Aids At Yayasan Peduli Kelompok Dukungan Teman Sebaya (YPKDS) In Makassar City

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ABSTRACT
HIV/AIDS is no longer a deathly disease but a disease that require long treatment. In the current era of HAART, PLWHA can live longer, but that does not mean that PLWHA live a satisfying and quality life. This circumstance makes PLWHA have to regularly consume antiretroviral therapy (ART) for a long time and even for life. This makes PLWHA vulnerable to various health problems such as; medication adherence, medication management, and side effects of drug use for a long time. Thus, the aim of this study is to see factors that may associate with the quality of life people with HIV/AIDS. This research was using a cross sectional study and the sample size was determined by using probability sample with multistage sampling technique. The selected location for conducted this research was Yayasan Peduli Kelompok Dukungan Sebaya (YPKDS) Makassar with total sample 67 respondents. The sociodemographic analyses found that that mostly respondents were male with percentage 3 times higher than female respondents; 48 and 19 respectively. Most of the respondent were Islam (89,6%), single (58,2%), and living together with their closest family members (62.7%). The respondents also mostly have a job with the monthly salary mostly under Rp. 1.000.000,- and most of them already under medication for less than or in 2 years, 40 and 50 respondents, respectively. Gender, period on medication, as well as stigma were associate with quality of life people with HIV/AIDS. The conclusion in this study was there were several factors that associate with quality of life people with HIV and need to further of analyses to create a better understanding.

Keywords: Stigma, Gender, Period on Medication, Quality of Live, HIV/AIDS

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BACKGROUND

Since it was first discovered in 1981, HIV/AIDS has become a serious global challenge and has become one of the main diseases in the global health system (1). Since it was first declared as a global problem, many strategic steps have been taken in an effort to better understand the disease process, human impact and response to the spread of HIV / AIDS (2). These efforts are very important in determining the most vulnerable population to HIV / AIDS, as well as determining the needs as well as the challenges that may be faced in solving this HIV / AIDS problem (2).

Globally, many efforts have been made to suppress and reduce the incidence of HIV / AIDS. Data from the United Nation for AIDS commission (UNAIDS) shows that globally there has been a decrease in HIV / AIDS prevalence, from 11.2% in 2002 to 6.6% in 2010 and to 4.6% in 2018. This emphasizes that significant progress has achieved globally. However, despite significant progress, this achievement seems not enough to reach the 2030's target, to end AIDS as a global health problem (3). This is influenced by the different policies and responses of each country (4).

The Asia-Pacific region is one of the regions that have made significant progress in efforts to control the spread of HIV / AIDS. Several countries such as Thailand, China and India have succeeded in reducing the spread of HIV / AIDS in populations at risk. Nonetheless, some countries such as Afghanistan, Bangladesh, the Philippines and even Indonesia tend to experience the opposite phenomena where the percentage of the spread of this disease tends to increase every year (3).

According to the Ministry of Health (2019) (5), the HIV / AIDS epidemiology in Indonesia is ranks 5th in Asia as the country most at risk for HIV / AIDS transmission. Although the number of new HIV cases decreased, from 1366 cases in 2017 to 1174 in 2018, there is a significant increases in the number of people living with HIV / AIDS; 620,000 in 2015 to 640,000 in 2018. This is exacerbated by the statistics that a quarter of the total incidence of new cases in Indonesia occurs in the adolescent to young adult age group, namely 15-24 years (3). According to Mulu et al., (2014) (6) globally, every day 6000 young people (aged 15-24 years) are infected with HIV / AIDS, where every minute there are more than 5 young people infected with this virus.

The increase in the number of people living with HIV / AIDS (PLWHA) is due to the existence of highly antiretroviral therapy (HAART) and its provision which is easy for PLWHA to obtain. In the current era of HAART, PLWHA can live longer, but that does not mean that PLWHA live a satisfying and quality life (7). This is because until now there is no drug or vaccine that can cure HIV / AIDS. This circumstance makes PLWHA have to regularly consume antiretroviral therapy (ART) for a long time and even for life. This makes PLWHA vulnerable to various health problems such as; medication adherence, medication management, and side effects of drug use for a long time. Therefore, it is very important to see what factors can affect the quality of life of PLWHA (7).

Previous studies have attempted to see what factors can affect the quality of life of PLWHA. Several factors include depression, stigma, the stage of HIV infection, the severity of symptoms of HIV infection, the ability to fulfill daily needs independently, work status, and social support (7,8,9)

The stigma of the environment around PLHIV can affect the process of preventing and treating PLHIV. PLWHA who feel stigmatized are not willing to take the test for fear of discrimination. In addition, PLWHA also have a fear of disclosing their status because they are afraid of receiving inappropriate treatment. This can result in PLWHA who lose their

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motivation and desire to go to health services for treatment and consult about their illness (10).

The development of HIV has become a disease that can have a negative impact both physically and mentally on people living with HIV / AIDS (PLWHA). With the development of treatment for HIV / AIDS today, assessing the quality of life of PLHIV is an important factor for public health. Many people with HIV / AIDS today face various social challenges, such as poverty, community stigma, depression and community culture that can affect their quality of life. South Sulawesi Province is in the 9th position nationally with the highest percentage of HIV / AIDS cases. However, there is very little research that attempts to analyze how these social factors can affect the quality of life of PLWHA, particularly in Makassar City. Therefore the aim of this study is to look at the factors that can affect the quality of life of PLWHA in Makassar City.

METHODS

This research was using a cross sectional study to describe some factors that may related to quality of life people with HIV/AIDS in Makassar City. The sample size was determined by using probability sample with multistage sampling technique. The targeted population was all PLWH in Makassar City. Nonetheless, due to some considerations such as the targeted population that too heterogeneous and financial consideration thus the accessible population was determined by using cluster sampling. Some reasons that underpinned the used of cluster sampling method were the targeted population were too heterogeneous and the area was too large so it was difficult for researcher and enumerator to conduct a data collection (11). The selected location for conducted this research was Yayasan Peduli Kelompok Dukungan Sebaya (YPKDS) Makassar. Reasons for choosing this Non-Governmental Organisation were this community was very active in mentoring the PLWH as well as to collecting the data from new case of HIV in Makassar City.

Due to COVID 19, the researcher thought that it might difficult for data collection, thus the sample size was decided by using Lemeshow Formula with significant value 90%, d value = 0.05 and p = 0.05 with total samples 51. Further consideration was also counted regarding some respondents that might drop out or several times answered the questionnaire so the total sample size that being collected was 67 respondents.

This research was conducting by using 3 questionnaires. First questionnaire for demography data that consisted of: gender, religion, marital status, family type, working status, salary, tribe and duration in medication. In seizing for the perceived of stigma, Berger HIV Stigma Scale Instrument was used. This Berger HIV Stigma Scale Instrument was adapted to Bahasa with total 25 questions and each question consisted of 4 answers using Likert scale; 1 for strongly disagree until 4 for strongly agree. While to see the quality of life of PLWH, WHOQOL-BREF Bahasa version was being adopted. This WHOQOL-BREF questionnaire was consist of 4 domains; physical health, psychological, social relationship and environment. The questionnaire was distributed through google form but first the researcher and enumerator gave an inform consent through also a google form.

The data then analysed by using SPSS 24 version. The data first analysed in univariate to see the distribution of each item and then to depict the relation among variables the data then analysed using cross sectional technique.

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Results and Discussion

Table 1. Demography Table

	N	%
Gender		
Male	48	71.6
Female	19	28.4
Religion		
Islam	60	89.6
Christian Protestant	5	7.5
Catholic	2	3.0
Status		
Married	18	26.9
Single	39	58.2
Widower	10	14.9
Family Type		
Nuclear Family	42	62.7
Extended Family	8	11.9
Alone	13	19.4
Other	4	6.0
Working Status		
Working	40	59.7
Not Working	27	40.3
Salary		
< 1.000.000	30	44.8
1.000.000 – 2.500.000	20	29.9
> 2.500.000	17	25.4
Duration on Medication		
≤ 2 years	47	70.1
> 2 years	20	29.9
Tribe		
Torajanesse	5	7.5
Buginesse	14	20.9
Makassar	45	67.2
TOTAL	**67**	**100**

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Table 2. Description of Stigma and Quality of Life People Living With HIV In Makassar City

Domains	Mean	Median	SD
Stigma			
Personalized Stigma	26.51	25	7.252
Disclosured	10.91	11	1.840
Public Attitudes	13.36	14	4.508
Negative Self-Images	7.51	7	2.608
Total Stigma	55.85	56	12.906
Quality of Life (QOL)*			
Physical Health	55.87	56	12.102
Psychological	56.66	56	12.882
Social Relationship	65.96	69	20.168
Environment	63.37	63	13.302
Total QOL	91.84	91	13.457

* All domain scores based on a 0-100 scale

Table 3. Univariate of Stigma and Quality of Life People with HIV

	N	%
Stigma		
Personalized Stigma		
High	37	55.2
Low	30	44.8
Disclosured		
High	62	92.5
Low	5	7.5
Public Attitudes		
High	35	52.2
Low	32	47.8
Negative Self-Images		
High	19	28.4
Low	48	71.6
Quality of Life		
Physical Health		
High	40	59.7
Low	27	40.3
Psychological		
High	41	61.2
Low	26	38.8
Social Relationship		
High	47	70.1
Low	20	29.9
Environment		
High	53	79.1
Low	14	20.9
TOTAL	**67**	**100**

This research tried to see some sociodemographic factors as well as how stigma may affect quality of life people live with HIV/AIDS. Data collection was conducted for one month and originally there were 73 respondents participated on online questionnaire. Nonetheless,

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after conducting double checked according to the inclusion criteria, only 67 respondents were eligible to be respondent for this research.

The sociodemographic analysis, table 1, depicted that mostly respondents were male with percentage 3 times higher than female respondents; 48 and 19 respectively. Most of the respondent were Islam (89,6%), single (58,2%), and living together with their closest family members (62.7%). The respondents also mostly have a job with the monthly salary mostly under Rp. 1.000.000,- and most of them already under medication for less than or in 2 years, 40 and 50 respondents, respectively.

Gender and period on medication were found have association with some domains on quality of life of PLWH. Gender were depicted has relationship with psychological and social relationship domains. Most of the respondent were males and also were described have high quality of life for psychological domains, 33 respondents, while most of women have low quality of life for this domain, 11 out of 19 respondents. Same phenomenon also depicted on social relationship domain, where there were 37 males have better quality of life score. This finding was similar with research conducted by Handajani et al. (2015) (12) that found males gender was factor that associated with QOL PLWHA. This finding also similar with finding on research conducted by Loutfy et al., (2012) (13) Bakiono, et al (2014) (14) and Oliveira et al., (2015) (15). Those finding portrayed pretty much the same phenomenon where women have lower quality of life in comparison to men.

This pretty much can be explained with the gender norms that put women as caregiver, mother and person in charge to provide care may worsen the stigma towards women that indirectly affecting their quality of life. Some cultural factors also may contribute to this finding. In some developing country and patriarchy like Indonesia, women were most likely economic and emotionally dependence towards their partner. This research's finding depicted that gender has relationship with psychological and social relationship domain. This can be explained that HIV/AIDS women were labeling as "dirty" diseased and unworthy and probably be blamed and shamed for being HIV/AIDS positive due to some belief that they were practicing "unusual" sexual behavior (13). Men, on the other side, were found have better quality of life. This was probably due to the some socioeconomic level better than female and men were better in dealing with the disease.

Period on medication was found has association with physical health and environment domain. This finding was similar with Handajani et al., (2015) (12) and Avelina & Idwan, (2019) (16). HIV/AIDS positive who were being treatment on ARV for less than two years would probably get low quality of life especially in physical health. This may be associated with they still struggling with the physical change that they felt during the early engagement to medication.

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Table 4. Cross Sectional Analysis on Factors Associated with Quality of Life People with HIV in Makassar City

	Domains				Total QOL
	Physical Health	Psychological	Social Relationship	Environment	
Gender	0.111	0.044	0.049	0.179	
Duration on Medication	0.032	0.335	0.548	0.002	
Stigma					
Personalized Stigma	0.122	0.183	0.113	0.048	
Disclosured	0.076	0.370	0.631	0.576	
Public	0.345	0.082	0.015	0.027	
Attitudes	0.016	0.144	0.010	0.196	
Negative Self-Images					
Total Stigma					0.030

Stigma was analysed by using Berger scale that was divided stigma into 4 domains, namely; personalized stigma, disclosure, public attitudes, and negative self-stigma. This research's funding regarding stigma (table 3) portrayed that most of the respondent feeling would be stigmatized when they disclosure their HIV's status (62 respondents). Second was personalized stigma with 37 respondents, followed by public attitudes with 35 respondents. Although overall score for stigma was relatively high, 43 respondents with high score for stigma, they still have positive self-images. This was proven with there were 48 respondents with low negative self-images. In general most of the respondent has high quality of life (64.2%). From 4 domains in stigma questionnaire (in table 4), personalized stigma and public attitudes associated with environment on WHOQOL questionnaire, with *p value* 0.048 and 0.027 respectively. Public attitudes also have relationship with social relationship with the *p value* 0.015. For negative self-images has relation with physical health and social relationship domains, *p value* 0.016 and 0.010 respectively. Overall score for stigma and QOL also has relationship with *p value* 0.030.

This finding was similar with Lindayani et al., (2018)(17) who also found the relationship between stigma and quality of life. Basri, (2018) (18) also found the similar finding on how stigma has an association with quality of life.

For 4 domains in quality of life questionnaire, environment has the highest percentages, second was social relationship, followed by psychological and lastly physical health domains. This finding was similar with research's finding that conducted by Oliveira et al., (2015)(15) who also found environment domain has the highest independence value. Nonetheless, Handajani et al., (2015)(12) found psychological domain as the highest value. Environment domain was assessing some trait in relation to physical safety and security, home environment, financial capability, health and social care quality, technology, leisure, physical environment and transport (15). The demography data of this research found that most of the respondent close to their health care facilities and most of them have duration of waiting time less than 30 minutes. This can be assumed that most of respondent found comfortable with their health facility. Further, most of respondent stayed or lived together with their close family members. Recognizing Indonesia's culture that has a strong family bounding, this could give security feeling towards HIV/AIDS positive. This was due to the fact that family can act as strong supporting factors for HIV/AIDS people (19).

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This study had several limitation such as the quite small sample size and cross sectional design, which unable to depicted a cause and effect relationship. However, the result provided a new insight and knowledge about the quality of life of HIV/AIDS people in Makassar City and what kind of social factors that may associate with it

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