

Quality of Life People Living with HIV/AIDS: Outpatient in Kramat 128 Hospital Jakarta

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ABSTRAK

Tujuan: untuk memberikan gambaran tentang kualitas hidup orang dengan HIV/AIDS di Jakarta, khususnya di Rumah Sakit Kramat 128, berdasarkan tingkat CD4 dan viral load (VL) serta lama terapi dengan antiretroviral (ARV). **Metode:** studi analisis cross-sectional dilakukan pada pasien rawat jalan di RS Kramat 128 Jakarta, periode November 2010 sampai Januari 2011. Kualitas hidup dinilai dengan instrumen WHOQOL-BREF. Data dianalisis dengan Chi-Square test, independent T-test, dan One-Way Analysis of Variance (ANOVA) test. **Hasil:** nilai dari empat domain kualitas hidup diurutkan dari yang terbesar yaitu domain psikologis (72,27), kesehatan fisik (70,10), lingkungan (65,59), dan relasi sosial (64,44). Terdapat perbedaan bermakna pada tingkat CD4 tinggi terhadap kualitas hidup keseluruhan ($p=0,000$) dan kepuasan kesehatan ($p=0,001$). Pasien yang diwawancara terlihat sehat secara fisik dan psikis, memiliki nilai kualitas hidup yang baik berdasarkan analisis statistik. Pada VL yang tidak terdeteksi memiliki kepuasan kesehatan yang baik ($p=0,012$). Demikian pula terapi ARV lebih lama (>1 tahun) memiliki kualitas hidup keseluruhan yang baik ($p=0,024$) dan kepuasan kesehatan yang baik ($p=0,003$). Hasil analisis tingkat CD4 dengan empat domain kualitas hidup menunjukkan hubungan bermakna terhadap domain kesehatan fisik ($p=0,001$) dan domain psikologis ($p=0,043$). Tingkat VL menunjukkan hubungan bermakna dengan empat domain kualitas hidup ($p<0,05$). Analisis lama terapi ARV dengan empat domain kualitas hidup, hanya bermakna pada domain kesehatan fisik ($p=0,015$). **Kesimpulan:** tingkat CD4 yang lebih tinggi, VL tidak terdeteksi, dan lama terapi ARV akan meningkatkan kualitas hidup pasien. Semakin tinggi kualitas hidup akan menyebabkan pasien memiliki kemampuan untuk mengatasi penyakitnya. Sehingga kualitas hidup yang lebih baik dapat menjadi tujuan pengobatan HIV dan indikator keberhasilan terapi ARV.

Kata kunci: kualitas hidup, HIV/AIDS, instrumen WHOQOL-BREF, ARV, tingkat CD4, viral load.

ABSTRACT

Aim: to provide an overview of the quality of life (QOL) for people living with HIV/AIDS (PLWHA) in Jakarta, particularly in the Kramat 128 Hospital, based on CD4 and viral load (VL) levels and the length of antiretroviral (ARV) treatment. **Methods:** a cross-sectional study performed at Kramat 128 Hospital Jakarta Outpatient Clinic from November 2010 to January 2011. Quality of life was assessed with the WHOQOL-BREF instrument. The data were analyzed using Chi-Square test, independent T-test, and One-Way Analysis of Variance (ANOVA) test. **Results:** the mean score in four domains of QOL in descending order were psychological (72.27), physical health (70.10), environment (65.59), and social relationships (64.44). There were a significant differences in overall QOL ($p=0.000$) and general health ($p=0.001$) between lower and higher CD4 levels. Patients who were interviewed look healthy physically and psychologically, have a good QOL based on statistical analysis. Patients with undetectable VL levels had better in general health ($p=0.012$), and those with longer ARV therapy (>1 year) had better overall QOL ($p=0.024$) and general health ($p=0.003$). Analysis with four domains of QOL

showed a significant relationship of CD4 levels with the physical health ($p=0.001$) and psychological domain ($p=0.043$). VL levels showed significant relationships with the four domains of QOL ($p<0.05$). Duration of ARV therapy showed a significant association only with physical health domain ($p=0.015$). **Conclusion:** higher CD4 levels, undetectable VL, and longer ARV therapy will increase patient's QOL. Higher QOL will make the patient have ability to cope with illness. So, a better QOL can be taken as indicator of successful ARV treatment.

Key words: quality of life, HIV/AIDS, WHOQOL-BREF, ARV, CD4 cells, viral load.

INTRODUCTION

Nowadays HIV/AIDS therapeutic efficacy is not only seen from the patients' clinical condition but also patients' quality of life (QOL).^{1,2} Implementation of ARV therapy can be succeed if the patient's QOL is good. WHO has defined QOL as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns.³ Many things can lead to decrease patients' QOL with HIV/AIDS such as due to disease progression, patients' disability, social stigma that exist in the society, long-life treatment, and side effects of treatment.⁴

Based on previous studies with 60 samples of patients with HIV/AIDS, showed that patients with low CD4 level have a lower QOL. In addition, female and low educational background have a lower QOL than male and high educational background.^{3,5} QOL of male patients is higher than women (46.10% : 37.98%).⁶ The importance of QOL leads us to achieve that endpoint in the treatment HIV/AIDS patients. Therefore we need to conduct studies on the patient's QOL especially in the marginal like people living with HIV/AIDS (PLWHA).

In Indonesia, QOL of PLWHA and ARV therapy progress were not yet known, so we do not know how much effect of ARV therapy to improve patient's QOL in Indonesia. In HIV treatment, we not only need ARV therapy but the important thing is need treat patient to increase QOL. Assessing QOL is useful for documenting the patients' perceived burden of chronic disease, tracking changes in health over time, assessing the effects of treatment, and quantifying the return on health care investment.⁷

In relation to the above, researchers conduct the study, especially at the Kramat 128 Hospital Jakarta so that the treatment given to PLWHA can be more integrated and holistic. The objective

of this study to provide an overview of the QOL for PLWHA in Jakarta, especially at the Kramat 128 Hospital Jakarta, based on CD4 and viral load (VL) levels and the long treatment with antiretroviral (ARV).

METHODS

This is a cross-sectional analytic study performed at the Kramat 128 Hospital Jakarta Outpatient Clinic throughout November 2010 until January 2011. Data were collected through direct interviews and medical records tracing. Inclusion criteria were patients willing to be interviewed, eligible to answer all the questions, and patients had received ARV therapy more than three months. Exclusion criteria were patients with incomplete medical record. Informed consent of all the respondents enrolled in the study was taken before start the interview. The respondent sampling method is a consecutive sampling, which is all outpatients PLWHA during the time period of study and minimum sample calculated using $n = Z^2pq/d^2$, which is Z (confidence interval) 99%, p (HIV prevalence in Indonesia⁸) 0.2%, $q = 1-p$, and d (degree of deviation) 2%. We get minimum sample 34 patients and there are 88 patients in three months.

The instrument that we use to evaluate QOL is WHOQOL-BREF. WHOQOL-BREF has 26 items grouped under four domains. The items under the domains are physical health, psychological, social relationships, and environment.

Physical health – dependence of treatment, energy and fatigue, mobility, presence of pain and discomfort, sleep and rest, activities of daily living, and perceived working capacity. Psychological – affect, positive self-concept, negative feelings, higher cognitive functions, body image, and spirituality. Social relationships – social contacts, family support, and sexual activity. Environment – freedom, quality of home environment, physical safety and security, involvement in recreational

activity, quality of health and social care, and accessibility of service.

There are two items examined separately, there are an individual's overall perception of QOL and an individual's overall perception of their health (general health/satisfaction with health). Each item uses a five-point Likert-type scale.

All 26 items were checked and scores ranging from 1-5. Scores of three negatively phrased items were reversed. Score were transformed to 0-100 scale. Cases with greater than 20% of missing data were deleted.

CD4 levels measurement was done by flow cytometry in Dharmais Hospital or Cipto Mangunkusumo Hospital. As well as the VL levels measurement was done in the same hospital, using the Polymerase Chain Reaction (PCR).

Statistical analysis was performed using statistical analysis software SPSS version 15.0. The Chi-Square test, independent T-test, and descriptive variables such as frequencies, mean, and standard deviations were used. One-Way Analysis of Variance (ANOVA) was performed for finding out significance difference between domain scores and clinical categories. Post-hoc analysis was performed using LSD to find out the pairs that contributed to the difference.

RESULTS

There were 88 outpatients participated in this study and the majority are males. The average age of respondents was 34.1 ± 7.4 years and the largest group was 30-40 years (64.8%). Based on the mode of transmission and the duration of the disease, 56.8% were through intravenous drug use (IDU) and 43.2% through sexual transmission. Nearly half of patients (45.4%) already suffering for more than three years. (Table 1)

The results showed most of respondents have good overall QOL and good general health (71.6% and 62.5%). From four domains of QOL (score 0-100), psychological domain had the highest value (72.27) and the social relationships domain had the lowest value (64.44). The other, in physical health and environment domain were 70.10 and 65.59, respectively. In CD4 measurements showed 22.7% (20/88) at the CD4 levels <200 cells/mm³ (low), 51.2% (45/88) between 200-500 cells/mm³, and 26.1% (23/88) >500 cells/mm³.

In VL measurements, 88.7% (78/88) of respondents had VL levels ≤ 399 copies/mL, 3.4% (3/88) had VL levels 400-49,999 copies/mL, 4.5% (4/88) had VL levels 50,000-499,999 copies/mL, 1.1% (1/88) had VL levels $\geq 500,000$ copies/mL, and 2.3% (2/88) of respondents did not conduct the examination. Based on the duration of ARV therapy, 18.2% (16/88) was <1 year, 30.7% (27/88) was 1-2 years, and 51.1% (45/88) was >2 years.

Table 1. Characteristics of subjects

Variables	n (%)
Sex	
- Male	70 (79.5%)
- Female	18 (20.5%)
Age range 23-60 years (mean\pmSD)	34.09 \pm 7.357
Levels of education	
- No education – junior high school	9 (10.2%)
- High school	50 (56.8%)
- > Diploma	33 (29%)
Marital status	
- Unmarried	28 (31.8%)
- Married	59 (67.0%)
- Divorced	1 (1.1%)
Occupation	
- Civil employee	3 (3.4%)
- Private employee	38 (43.2%)
- Entrepreneur	32 (36.4%)
- Not working	5 (5.7%)
- Others	10 (11.4%)
Duration of HIV	
- <1 year	13 (14.8%)
- 1-2 years	25 (28.4%)
- 2-3 years	10 (11.4%)
- >3 years	40 (45.4%)
Transmission of HIV	
- IDU	50 (56.8%)
- Sexual intercourse	38 (43.2%)

Comparison of QOL and general health assessment according to CD4, VL, and duration of therapy is depicted in Table 2 and 3.

The analysis of relationship between CD4 levels with four domains of QOL showed a

Table 2. Comparison of overall quality of live according to CD4 level, viral load, and duration of ARV treatment

	Not good	Good	p
	n (%)	n (%)	
CD4 Levels			
- <200 cell/mm ³	13 (65.0)	7 (35.0)	0.000
- 200-500 cell/mm ³	7 (15.6)	38 (84.4)	
- >500 cell/mm ³	5 (21.7)	18 (78.3)	
VL Levels			
- Undetectable	20 (25.6)	58 (74.4)	0.108
- Detectable	5 (50.0)	5 (50.0)	
Duration of ARV			
- <1 year	9 (56.3)	7 (43.8)	0.024
- 1-2 years	6 (22.2)	21 (77.8)	
- >2 years	10 (22.2)	35 (77.8)	

Table 3. Comparison of general health according to CD4 level, viral load, and duration of ARV treatment

	Unsatisfactory	Enough	Satisfactory	p
	n (%)	n (%)	n (%)	
CD4 levels				
< 200 cell/mm ³	7 (35.0)	8 (40.0)	5 (25.0)	0.001
200-500 cell/mm ³	3 (6.7)	9 (20.0)	33 (73.3)	
> 500 cell/mm ³	1 (4.3)	5 (21.7)	17 (73.9)	
VL Levels				
Undetectable	8 (10.3)	17 (21.8)	53 (67.9)	0.012
Detectable	3 (30.0)	5 (50.0)	2 (20.0)	
Duration of ARV				
<1 year	6 (37.5)	6 (37.5)	4 (25.0)	0.003
1-2 years	1 (3.7)	5 (18.5)	21 (77.8)	
>2 years	4 (8.9)	11 (24.4)	30 (66.7)	

significant relationship with physical health ($p=0.001$) and psychological domains ($p=0.043$). This means that respondents with CD4 levels <200 cells/mm³ had worse physical and psychological health compared to respondents with CD4 levels >500 cells/mm³. (**Table 4**)

Analysis of the four domains QOL scores showed that respondents with undetectable VL have better score in all domains (**Table 5**). The same was found on the relationship between duration of ARV therapy with the QOL, especially in the physical health domains ($p=0.015$), respondents with ARV therapy <1 year showed poorer physical health domains compared with respondents who use ARV >2 years. (**Table 6**)

Table 4. Post Hoc ANOVA test between CD4 levels with four domains of QOL (LSD test)

Variables	CD4 Levels	p value	CI 95%	
	A v.s. B			
Physical health	A v.s. B	0.026	0.94	14.41
	A v.s. C	0.001	5.81	21.88
Psychological	A v.s. B	0.598	-5.44	9.39
	A v.s. C	0.043	0.31	17.80
Social relationships	A v.s. B	0.376	-4.31	11.30
	A v.s. C	0.155	-2.60	16.02
Environment	A v.s. B	0.227	-2.56	10.60
	A v.s. C	0.129	-1.79	13.90

A=CD4 >500 cell/mm³; B=CD4 200-500 cell/mm³; C=CD4 <200 cell/mm³

Table 5. Independent T-test of QOL in the four domains according to VL levels

Variables	QOL scores		p value
	Detectable	Undetectable	
Physical health	59.17	71.50	0.008
Psychological	63.33	73.42	0.041
Social relationships	53.75	65.81	0.018
Environment	55.31	66.91	0.007

Table 6. Post Hoc ANOVA test between duration of ARV therapy with four domains of QOL (LSD test)

Variables	Duration of ARV		p value	CI 95%	
	>2 years v.s. 1-2 years				
Physical health	>2 years	1-2 years	0.826	-5.85	7.32
	>2 years	<1 year	0.015	1.97	17.71
Psychological	>2 years	1-2 years	0.485	-9.69	4.64
	>2 years	<1 year	0.396	-4.89	12.24
Social relationships	>2 years	1-2 years	0.610	-5.51	9.34
	>2 years	<1 year	0.186	-2.92	14.83
Environment	>2 years	1-2 years	0.495	-8.49	4.14
	>2 years	<1 year	0.831	-6.74	8.36

DISCUSSION

The average age of respondents was 34.1±7.4 years and the largest group was 30-40 years. The number of males and females were 79.5% and 20.5%. Most of them were married (67%). Respondents' education levels were quite high,

more than three-quarters over high school education. Directorate General CDC & EH Ministry of Health Republic of Indonesia⁴ and Wig et al⁹ (2006), reported that most PLWHA are male, productive age, and married status. So, there were similarities in characteristics of the respondents in both studies with this study.

The transmission of disease in our study was 56.8% through IDU and 43.2% through sexual activity, while in the study of Wig et al⁹ (2006), it was 71.7% through sexual activity, 15% through blood transfusions, and 13.3% through other transmission. Recent developments in clinical testing and treatment for PLWHA improved survival and QOL, it became an important focus for researchers and health workers.¹⁰

Various social problems faced by PLWHA such as social stigma, poverty, depression, violence, and cultural beliefs will affect the QOL. Not only affects on physical health but also mental and social health, and then it can cause various problems affecting daily activities and patients interest.¹¹ Several factors were associated with QOL for PLWHA, such as males gender, young age, higher socio-economic status, and employee. These were reported in international literature, improved the four domains of QOL.¹²

Assessment of QOL consists of overall QOL, general health, and perception QOL in four domains (physical health domain, psychological domain, social relationships domain, and environment domain). In our study, there were three-quarters of respondents with good QOL (71.6%), 27.3% with adequate QOL, and only 1.1% with poor QOL. Based on general health, there were two-thirds of respondents (62.5%) expressed his satisfaction on health, 25% felt fairly satisfied, and 12.5% were not satisfied with his health.

Based on the average value of the four domains of QOL, psychological domain showed the highest value (72.43), followed by physical health domain (71.43), then environmental domain (65.59) and the lowest values in the social relationships domain (64.44). However, Nirmal et al³ (2008), got the highest value on the environmental domain, followed by psychological and physical health domain, and then the lowest in the social relationships domain. But, Wig et al⁹ (2006) got the highest value in the social relationships domain and the lowest value in the environment domain.

Social relationships domain measure individual social relationships, social support, and sexual activity. Thus the low value in the social relationships domain in this study showed that the respondent limited in his/her personal relationships, and social support from friends was also lacking. It may be caused by the fact that the respondents may shy away from the environment as well as their friends and the persistence of social stigma against PLWHA and decreased friends support for them. Similarly, respondents also felt less satisfied in their sexual relationships, because respondents may have to use a condom or a spouse also restricted sexual activity.

Psychological domain was the highest value in our study. This domain assessed bodily image, negative feeling, positive feeling, self esteem, spirituality/religion beliefs and thinking, learning, memory, and concentration. This means that respondents in this study had received their condition of disease, so that negative feelings, sad, and disappointed had reduced, increased self-esteem, and more belief in God. Most of the respondents in Kramat 128 hospital have a medium-high economic status, well educated, and have a job, so they have more positive attitudes towards illness and treatment. Besides that, most respondents had improved health conditions from measurements of CD4 and viral load levels.

On examination of CD4 levels, only less than a quarter of respondents (22.7%) with CD4 levels <200 cells/mm³, the majority (51.2%) between 200-500 cells/mm³, and 26.1% with CD4 levels >500 cells/mm³. CD4 levels measurements on the study of Wig et al⁹ (2006) were 46.4% respondents with CD4 levels <200 cells/mm³, 53.6% respondents with respondents with CD4 levels 200-500 cells/mm³, and no respondents have CD4 levels >500 cells/mm³. Grierson et al¹³ (2005) got 47.3% respondents with CD4 levels >500 cells/mm³, 33.9% respondents with CD4 levels 250-499 cells/mm³, and 18.8% respondents with CD4 levels 0-249 cells/mm³. So, in our study and Grierson et al¹³ (2005) we found that respondents with high CD4 levels were comparable to the study of Wig et al. This is because some respondents in our study loss to follow up during the treatment and over two years of ARV therapy. Our study also showed more than half of respondents (88.7%) have undetectable VL (<400 copies/mL). Compared to the study of

Grierson et al,¹³ there were 57.5% respondents with VL levels <500 copies/mL and 42.5% respondents with VL levels >500 copies/mL.

The relationship analysis between CD4 levels with four domains of QOL showed a significant relationship to the physical health and psychological domains. The respondents with CD4 levels <200 cells/mm³ had a lower score of QOL (13.84 points) in the physical health domain and 9.15 points psychological domain compared to respondents with CD4 levels >500 cells/mm³. So the respondents with the lowest CD4 levels had worse QOL in the physical health and psychological domain compared to those with CD4 levels >500 cells/mm³. Similarly, the respondents with CD4 levels 200-500 cells/mm³ had a scores of QOL reduced by 7.68 points in physical health domain and 1.97 points in psychological domain compared to respondents with CD4 levels >500 cells/mm³. This means that lower CD4 levels is associated with worse QOL of physical and psychological health. The same situation was found in Nirmal et al³ (2008), that value of QOL was in a linear correlation with CD4 levels.

We analyzed relationship between VL levels with overall QOL, general health, and perception QOL in four domains. The result showed a significant association in general health and all domains. Lower VL levels and higher CD4 levels reduced symptoms of HIV and increase hemoglobin, which is an immunological/clinical indicator for better QOL.¹⁴

Abera et al¹⁵ (2010) reported that respondents with CD4 levels >200 cells/mm³ had a higher QOL scales, except social functioning and mental health than those with CD4 levels ≤200 cells/mm³. Similarly, an advanced stage of HIV patients, according to WHO definition and CD4 levels showed better QOL in both mentally and physically compared with early stage of HIV patients.¹⁶ It was because at an advanced stage of HIV/AIDS has done quite long ARV therapy, so that symptoms were reduced, increased CD4 levels, lowered VL levels, and improved QOL. Since the ARV discovery, morbidity and mortality of HIV infection has declined sharply in the world. Clinical studies were conducted from 2003-2006 reported that only 5% (2/41) ARV resistant patients and obedience to treatment plays an important role in increased immunity.¹⁷

Wang et al¹⁸ (2009) proved that obedience to ARV therapy was associated with increased immunity of PLWHA and contributed to increase CD4 levels. Mannheimer et al¹⁹ (2002) found that respondents who reported 100% obedience to ARV therapy had better virology and immunology after twelve months therapy. Yu et al²⁰ (2005) reported that the fewer drugs doses and not obedient in ARV therapy were factors that slowed to increase CD4 levels.

Analysis of long ARV therapy with four domains of QOL, showed a significant association only in one domain, physical health domain (p=0.015). Studies with a large number of samples in France proved a positive relationship between patients QOL with obedience to ARV therapy for one year and in patients who were not obedient in ARV therapy had worse QOL.²¹ The same situation was found in Liu et al²² (2006), respondents who were not obedient in ARV therapy had lower mental health level than respondents who were obedient in ARV therapy. Cohort study conducted by Mannheimer et al²³ (2005), showed that 100% obedience to ARV therapy during the first one year therapy increased QOL significantly. The same was found in China¹⁸, that the obedience to ARV therapy was significantly associated with the five aspects of QOL for the better result, namely physical functioning, general health, vitality, social functioning, and mental health. Abera et al¹⁵ (2010) reported that respondents who did ARV therapy over 12 months had an average score of all QOL domains higher than in those who did less than 12 months therapy. Even Applebaum et al²⁴ (2008) found that high obedience to ARV therapy affected patients QOL and was one indicator of well-being, including psychological, social, and physical health. According to McKinnon et al²⁵ (2010), that highly active ARV therapy (HAART) improved QOL because of the similarity in the speed and extent of immunity improvement.

CONCLUSION

From our discussion it is shown that higher CD4 levels, undetectable VL, and longer ARV therapy will increase patient's QOL. Higher QOL will make the patient have ability to cope with illness. So, good QOL can be taken as the goal for HIV treatment in order to have a successful of ARV therapy.

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