Quality of Life and Individual Adjustment of People Living with HIV/AIDS (PLWHA)

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Abstract: Having a good quality of life is a hope of everyone. Some factors are suspected to affect the quality of life such as adjustments to family and personal life, interpersonal relationship, and internal factors such as self-concept. This study aims to examine empirically the relationship between individual adjustment and life quality of people with HIV / AIDS. The research design employed was correlational quantitative. The subjects who were involved in this research were 73 people with HIV / AIDS (37 males and 36 females). The measuring instrument used was Sack Sentence Completion Test (SSCT) to measure family adjustment problem, self-concept problem, sexual adjustment problem, interpersonal relationship problem and World Health Organization Quality of Life Bref Version (WHOQOL-BREF) to measure quality of life. Analyzed using multiple regression, the data showed that problems of family adjustment, adjustment of sexual area, adjustment of interpersonal relationship, and self-concept problem simultaneously do not correlate significantly with quality of life. While partial correlation analysis resulted self-concept has significant correlation with quality of life. It resumed 9.5% of participants experienced family adjustment problems, 12.3% experienced problem with adjustment of sexual areas, and 5.5% experienced self-concept problem. Their quality of life in average is well and there are no significant differencies between male and female both in quality of life and individual adjustment.

1 INTRODUCTION

Indonesia firstly found HIV/AIDS in 1987 in Bali. It has been widespread in 386 districts. The case is currently at number 13 in the world. In 2015 when the MDGs (Millennium Development Goals) are achieved, HIV / AIDS included the third target that is difficult to realize. According to the opinion of the Directorate General of Disease Control and Environmental Health, since 1987 until around June 2014, the total number of HIV infected in Indonesia has reached 142,950 people and 56,623 are known to have AIDS (Superkertia dan Astuti 2016).

Individuals who are diagnosed with HIV initially may experience feelings of fear, anxiety, depression and even despair. This makes them feel shunned by the surrounding environment due to infection they suffered. While socially, people with HIV tend to get discrimination from society in the form of rejection, evasion, and also exile. People with HIV / AIDS are also often associated with negative behaviors caused by infection, e.g. homosexuals, prostitution, commercial sex workers, bisexuals, and the consequences of using drugs with needles. People affected by HIV / AIDS virus may not be derived from negative behavior, but can occur due to blood transfusions and infection during intercourse (Lubis dan Sarumpaet 2016).

Individual's quality of life closely refers to human's ideal life or perfect life to be achieved and desired by every individual. Oucneke & Rubenfire (Nyamathi dan Ekstrand 2017) stated that the quality of one's life depends heavily on the satisfaction of life as the acceptance of life in each individual. (Calman 1987) suggested that quality of life is directly related to one's overall well-being based on experience in life. According to (Stewart dan King 1994), quality of life is the degree to which an individual feels happy with an important choice in his life.

People with HIV / AIDS in everyday life are required to be able to deal with every problem in their lives. The problems faced by PLWHA are not only physically but psychologically, socially, and economically (Smeltzer dan Bare 2002). The complexity of the problems faced has an impact on

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the quality of life of PLWHA. Quality of life is a perception of one's feelings of functional abilities impaired caused by disease attacks (Fayers dan Machin 2007). Physical problems experienced by PLWHIV occur because the immune system decreases progressively as a source of susceptibility to disease infection. The social problems experienced by HIV sufferers are related to the negative stigma of the environment, affecting the quality of life that leads to mental, social and physical health. Quality of life is not only seen from the function of a person in daily activities, but also a person's perception of health that can affect his attitude in the life or quality of a person (Bello dan Bello 2013).

Quality of life refers to a picture of every person about a life such as a purpose of life, interpersonal relationships, self-esteem development, personal control, intellectual capacity and material (Sarafino 2006). It is also included in the achievement of individual success in obtaining certain conditions Mc.Call (Oliver dan Huxley 1997). The more prosperous and experienced, the easier someone achieves the goal in certain circumstances, Lehman (Diatmi dan Fridari 2014). The level of the simplest quality of human life is the standard and the degree of goodness and perfection of Schmandt and Bloomberg (Oliver dan Huxley 1997). It becomes the achievement of the ultimate goal for an individual, whereby a person achieves a more meaningful quality of life by exceeding a certain purpose.

Kahneman, Diener, & Schwarz (1999) argue that quality of life is a subjective process of life, which makes it more varied. Koot & Wallander (2013) mention there are three components to measure the quality of life of a person, among others: objective, subjective, and interests. The objective component is closely related to the life of a person. The second component is interconnected with the individual's judgment on his or her life and circumstances, while the latter component is seeing that how important an aspect can affect the life and quality of life itself. Quality of life is a person's perception of his life which can be seen from the system of values in society, the context of the culture, the purpose of life, the hopes, and the things that become individual judgments (WHO 2013). In addition Moons, Marquet, Budst, & de Geest (Aminarista dan Hadisaputro 2016), it is referred as a condition of a person seen from several important aspects of his life.

Based on the World Health Organization of Life (Bilington 2004) quality of life has 6 domains i.e. physical health, social relationships, psychological well-being, independence, environment and spiritual level. The measurement of quality of life has suggested merging domain physical health and level of independence, and merging domain psychological and spirituality. World Health Organization Quality of Life (WHOQOL) is then made into an instrument of World Health Organization Quality of Life Bref Version (WHOQOL-BREF) where 6 dimensions can be made again into 4 domains of physical health, social relationship, psychological well-being, and environment.

Felce & Ferry (1995) reveals that the aspects of quality of life are grouped into four major parts i.e. physical well-being aspects which includes health, fitness aspects, physical security and mobility. Then, the next aspect is material well-being which consists of environmental quality, security, transportation, ownership, stability, opinions and privacy. The third aspect refers to social well-being which consists of one's involvement with society and interpersonal relationships. The latter is development and activity, emotional well-being which consists of satisfaction in the fulfillment of life, affects and mood, spirituality, the self-confidence and status of a person.

Power, Lopez and Snyder (WHO 2004) stated physical health (activities related to daily life such as fatigue, drug dependence, pain, discomfort, less sleep and rest and individual work capacity), psychological aspects (such as self-esteem, personal or spiritual beliefs, thinking patterns, learning process, memory, concentration, body image and appearance as well as positive and negative feelings), social relation aspects (related to social support, sexual activity, interpersonal relationships), and environmental aspects that include safety and security, freedom, finance, health, care, home environment, skills, opportunity to participate, and physical environment i.e. water, climate, transportation and pollution.

One factor which would affect quality of life is culture. Quality of life varies affected by cultures that exist in certain areas (Fadda dan Giuletta 1999). Another factor is gender. One aged under 40 years has monthly income of more than 300 USD, having an education beyond the secondary level, or being employed has a positive correlation with quality of life (Yang and Thai 2016), psychosocial and sociodemographic factors predicted quality of life at highly active antiretroviral therapy (HAART) on a year treatment of ARV and financial dependence on others was the only remaining predictor after

controlling the time in samples in Uganda (Stangl and Wamai 2007).

Psychological factors and income take an important role in quality of life of PLWHA. This is in line with the study which was conducted by Friedland, Renwick and Mccoll (1996) who found that income, emotional social support, and problem-oriented and perception-oriented coping are positively related to quality of life, while tangible social support and emotion-oriented coping strategy are negatively related to quality of life. Surprisingly, severity symptom has no correlation at all. Furthermore, they explained that close friends provided most type of support. The study which was conducted by (Bekele dan Rourke 2013) showed that perceived social support has significant direct effect on both physical and mental health mediated by depressive symptoms on PLWHA in Canada. This fact a line with the findings of Hou, Chen, Liu, Lai, Lee, Lee, Chang, Chen, Ko, Shu, and Ko (2014) on PLWHA in Taiwan i.e. quality of life significantly has positive correlation with social support and ARV (antiretroviral) therapy and has negative correlation with depression and study conducted by (Asante 2012) showed that social support was negatively associated with depression, stress, and anxiety.. In addition, the study which was conducted by (Manhas 2013) in India showed there is a significant positive correlation between self-esteem and quality of life.

Health related quality of life is severely comprised in people living with AIDS (PLWHA) in South Africa in stages 3 and 4 and have limitations in the four domains of mobility, usual activities, pain/discomfort and anxiety/depression (Hughes and Jelsma 2004). The finding of (Brett dan Gow 2012) showed that the quality of life of an individual is also influenced by the circumstances of the present and the past. The factors which can affect a person's quality of life are gender and income. The amount of income affects lifestyles starting from residence, living habits, food consumption and psychological conditions (Khumsaen, Aoup-por dan Thammachak 2012), Age also affects the quality of life. An older person tends to be better able to evaluate himself for the better based on previous life experiences, compared to the young (Alec & Philips, 2014; Karkashadze & Gates, 2017). The same is true with education, where the higher educational level the higher quality of life (Handajani, Djoerban dan Irawan 2012). Occupation and marital status (Noor 2007) does either. An individual's closeness relationship has a better quality of life, both emotionally and physically (Myers dan Diener 1995). The next is hope, the same feelings with other individuals, and aspirations (O'Connor 1993), chronic illness has a negative impact from mild to severe on a person's quality of life which causes daily activities to be disrupted or altered (Monali, Amit dan Steven 2006). Based on research results, Djoerban & Irawan (2012) also stated that the quality of life is influenced by the physical health domain of 70.10% and the relationship with others by 64.44%.

The purpose of our study is to assess quality of life and individual adjustment of PLWHA and to examine association of individual adjustment and quality of life and domain-specific of individual adjustment and quality of life.

2 METHODS

Two Thousands of PLWHA in Victory Plus Foundation Yogyakarta were involved in this study as population. The samples were obtained by purposive sampling technique. The participants consisted of 36 women and 37 men with criteria of ranging from 25 to 57 years old with average age 36.2 years and domiciled in DIY Province. The participants in this study were PLWHA who are actively involved in activities organized by the Victory plus Foundation and have good adherence for ARV treatment (antiretroviral treatment). The occupations include a supporter of HIV-infected peers (members of peer support groups) (5.48%), private employees and freelancers (56,16%), self-employed / traders (17.81%), housewives (19.18%), and farmer (1.37%). The average time period of having infected with HIV for 2 years, with a range of time duration infected between 6 months to 10 years. There were 20 participants who are known to have been infected with HIV for 5 years and among them 1 person has been infected for 10 years.

The data were collected using quality of life scale from *World Health Organization Quality of Life Bref Version* (WHOQOL-BREF) which covers the aspects of quality of life (Lingliang, Derson dan Shuiyuan 2004), among others, health (activities related to daily life, drug and medical aid dependence, energy and fatigue, mobility and pain, sleep pattern and work capacity. The estimated reliability of life quality scale was $\alpha = 0.871$. Sack Sentence Completion Test (SSCT) is used to collect data related to individual adjustment problems. It consists of 60 items divided into four main aspects: family adjustment (12 items), sexual adjustment (8 items), adjustment of interpersonal relationships (16

items), and self-concept (24 items). In addition, semi-structured interviews were conducted on five PLWHA participants, Vice President of Victory Plus Foundation, and coordinator of peer support group.

The data were collected in 3 months from October to December 2017. The interviews were conducted on 3 to 5 October 2017. WHOQOL-BREF and SSCT were administered to 77 people living with HIV / AIDS. The data were then collected in three places: Sardjito General Hospital Yogyakarta, "X" Hotel along with the capital grant from the Social Service for PLWHA, and Victory Plus Yogyakarta office.

The 77 participants in this research filled the data of WHOQOL-BREF, while 75 of them filled SSCT completely but 4 of them were not, so that there were 73 data sets which then were analyzed. Data analysis in this research used regression analysis and partial correlation.

3 FINDINGS

The descriptive statistic analysis on the measured data using WHOQOL-BREF and SSCT resulted below.

Table 1. Score Description of Quality of Life and Individual Adjustment (N=73, male =37, female=36)

Variables	Sex	Mean	Std. deviation	t	p value
Quality of life total		101.04	10.418		
Quality of life	male	100.46	10.232	-0.481	0.632
	female	101.64	10.718		
Physical health	male	23.62	2.762	0.491	0.625
	female	23.31	2.734		
Psychological well-being	male	31.35	3.545	-0.238	0.813
	female	31.56	3.783		
Social relationship	male	15.41	2.327	-1.002	0.32
	female	15.94	2.267		
Environment	male	30.08	3.483	-0.869	0.388
	female	30.83	3.902		
Individual Adjustment total		19.1	8.369		
Individual Adjustment	male	18.3	7.799	-0.825	0.412
	female	19.92	8.952		
Adjustment to family	male	3.97	2.891	-0.773	0.442
	female	4.58	3.805		
Adjustment to sexual area	male	2.7	1.884	-0.042	0.967
	female	2.72	2.092		
Interpersonal adjustment	male	2.27	2.329	-0.355	0.724
	female	2.47	2.535		
Self-concept	male	9.35	3.765	-0.833	0.407
	female	10.14	4.297		

Based on t test there are no significant differencies between male and female both quality of life and individual adjustment in each specific-domain.

The norms of categorization based on hypothetic norm as a whole are presented in the table below:

Tabel 2. Score Categorization of Quality of Life

Norms	Categorization	Total	%
103,95< x	Very High	24	32.88%
86,65< x ≤ 103,95	High	46	63.01%
69,35 < x ≤ 86,35	Fair	3	4.11 %
52,05 < x ≤ 69,35	Low	0	0 %
x ≤ 52,05	Very Low	0	0 %
	Total		100%

Furthermore, multiple regression test was conducted obtaining value R = 0.286 with the value of F = 1.150 at p = 0.209 (p >0.05). This means that simultaneously there is no significant correlation between family adjustment problem, sexual adjustment issues, interpersonal relation problem, and self-concept problem with PLWHA quality. The next analysis was partial correlation by examining the relationship of self-concept problem with quality of life by controlling the aspect of adjustment problems to family, sexual field, and interpersonal relationship problem obtaining value rx-1y = -0.261, p = 0.026 (at los 0.05). This means that there is a significant negative correlation between self-concept problem with PLWHA quality of life. Other result of partial correlation test show that there is no significant correlation between adjustment problems to family, sexual field, interpersonal relationship and quality of life.

Individual adjustment problems obtained from the measurement using SSCT were known from 73 participants that there are 8 participants who have problems with family adjustment, 9 participants have problems in adjustment of sexual area, and 4 participants have problem with self-concept. While related to interpersonal relations, no participant has significant problems that impact their daily life.

Family adjustment problem was experienced by six female participants and two male participants. The problems interfered the female group among others are (a) often quarreled in the family for assuming that the problems she experienced started from her father who treats her roughly and can not act as a good head of household, never been cared by her father and feels jealous when she saw a happy partner because her married life is hollow (b) having a father but not feeling the father's role in her life, the father does not accept her presence and she lives a fake marriage life, (c) the father treats other family members rudely so that she makes her escape by way of changing sex partners (d) ignored by her father and irresponsible of her family, broken home, (e) denying father figure in her life, (f) coming from an unharmonious family, no communication with mother and father. While the male participants are known to have problems with the figure of a father who since childhood is not known, as well as a father who does not care and irresponsible eventhough he has a mother who loves him.

There were nine participants who have problems with the adjustment of sexual area: six males and three females. The problems encountered include (a) being unsatisfied in his or her sexual life, undergoing complicated marriages, and dominant and abusive wives, (b) blaming all women as unkind and marriage as impossible, (c) undergoing meaningless marriage, never being satisfied with the sexual life, and having a negative view of all women, (d) having a high sex drive but never getting satisfaction from their partner, (f) viewing the relationship with the opposite sex only for sexual impingement, while the feeling only occurs in same sex, (g) the mother figure is considered favoritism. In the female subject group, the problems experienced were (a) being regretful on and on of marriage that caused them have HIV infection, (b) being not interested in marriage because they think they were false but have very high sexual urges.

There were three males and one female who have problems related to self-concept that is quite disturbing their life. (a) They experience very slumped, sad, and embarrassed with the family because of having a deviant sexual orientation, (b) since childhood, they feel not in accordance with their gender, wanting to be fully women who are biased to marry and give birth to children, (c) Afraid to face future because of multiple partners, the consumption of drugs and infected with HIV, and (d) feel so guilty to parents that it makes them difficult to make decisions and act.

4 DISCUSSION

The findings of this study indicate that simultaneously the problems of individual adjustment (family adjustment problem, sexual adjustment issues, interpersonal relation problem, and self-concept problem) have no significant correlation with the quality of life of PLWHA. Partial correlation analysis showed that the self-concept problem experienced by PLWHA in Victory Plus foundation is negatively correlated with quality of life.

The quality of life of the participants is generally in a good category. All participants in the study generally do not have significant problems that could interfere with their daily lives related to interpersonal relationships. They already have good self disclosure with people around them and have good peer support (fellow PLWHA), as well as family communication. This is in line with the findings of Qiao, Li, Zhou, Shen, and Tang (2016) who examined the PLWHA in China showing that quality of life is linked to open and effective openness of HIV status to partners and open family communication.

The study by Wani & RS (2017) stated that the study consisted of a sample of 60 AIDS patients with the same number of male and female, finding that males who already had wives have better quality of life than women who are single, also receive more social support than unmarried female patients. The results of this study are reinforced by the results of research by Simboh, Bidjuni, & Lolong (Simboh and Bidjuni 2015) that someone in this life has such problems that require the support of others in settlement.

Based on the finding of the study by (Jin dan Liu 2015), it is stated that there is no change in the quality of life of HIV patients after antiretroviral treatment for 6 months. HIV / AIDS places a heavy burden not only on their physical health but also good mental health. Meanwhile, the quality of life of PLWHA is affected by several factors, such as CD4 count, viral load, social support, spiritual well-being, educational level, drug users by injection, and stigma. While the results of the study (Pitt dan Myer 2009)reported otherwise, that antiretroviral therapy can improve the quality of life of people living with HIV but with the incidence of clinical symptoms and complications so as to feel pain and discomfort due to the side effects of treatment. The effect is most strongly felt by stage 3 and 4 patients. Although it can improve the quality of their life, this treatment takes a long time and requires a group of observers with a long time to know the improvement of quality of life.

The World Health Organization (WHO) also stated that healthy condition is not only free from physical illness but also the achievement of qualified well-being. Anderson, Pramudho, & Sofro (2017) argued that quality of life can be interpreted as a person's perception of the cultural context of their cultural values of residence in relationships and aims, hopes, and cares for physical health, psychology, independence, social relations, personal beliefs, and the environment.

There are some factors that may affect the process of antiretroviral therapy, as in the results of the study by Sugiharti, Yuniar, & Lestary (2014) that there are 9 out of 11 people with HIV / AIDS who have a level of ARV treatment adherence 95%, factors that play an important role including family support, peer support, HIV-caring communities, and factors that come from an individual. In addition to the factors that need to be taken into account, there are also factors that can inhibit the antiretroviral treatment, such as saturation when continuously consuming drugs, side effects caused by drugs, negative stigma of the community and the cost of treatment.

Based on findings in this research there is no one has problems in adjustment of interpersonal relationship. But there are several respondents have adjustment problems in sexual area and adjustment to family. Surprisingly their problems in sexual area and adjustment to family have no significant impact to their quality of life. It can be understood that the respondents in this study were already open HIV status and were active members in non-governmental organizations that facilitated the needs of PLWHA, such as access to health services, antiretroviral drugs, and peer support groups. This makes active members feel togetherness and brotherhood so that they do not experience significant problems in social relations, psychological well-being, environment, and physical health.

Self-concept problem has negative significant relationship with quality of life of PLWHA. Furthermore, several respondents have self-concept problem that affect their quality of life. Self-concept in its development is influenced by the social environment. The existence of a negative stigma from the community lead someone develop a negative self-concept. The study conducted by Zhang & Li (2016) in China reported that higher perceived and internalized stigma were more likely to be imposed on emotional and physical burdens.

5 CONCLUSION

In conclusion, the quality of life of PLWHA has a strong relationship with self-concept. This self-concept problem is closely related to the adjustment problems of family, sexual field, and interpersonal relationships. Therefore, adequate interventions are needed to deal with the problem of self-concept so that the quality of life of PLWHA becomes better.

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