International Journal of Health Literacy and Science 2 (1) (2024)
International Journal of Health Literacy and Science
https://ihelis.com

# Phenomenology Study on Health-Related Quality Of Life For People With HIV/AIDS at Victory Yogyakarta

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## Article Info

*Article History*

Submitted: October 4, 2023

Revised: March 23, 2024

Accepted: June 19, 2024

*Keywords:*
*HRQOL; HIV; AIDS*

## Abstract

HIV/AIDS is a disease that continuously develops and becomes a global health problem either in advanced or developed countries. The condition transformation of chronic HIV patients can be handled by improving Health-Related Quality of Life (HRQOL). HRQOL program has become an important focus of WHO aiming to improve the society quality in maintaining the level of human health. This study aimed to know the Health-Related Quality of Life of ODHA (Orang dengan HIV AIDS) at Victory Foundation Yogyakarta related to physical, psychological, mental-emotional, and religious aspects at Victory Plus Foundation Yogyakarta. This research used a qualitative research method with a phenomenology approach and an in-depth interview used this method. The information was obtained through deep interview techniques and observation of eight ODHA informants. The result of HRQOL qualitative analysis on ODHA is based on four various aspects. Based on the physical aspect, obtained skin rash, reddish spots, whitened or blackened scars, the initial symptom of depression, and major depression. The mental emotion of informants gets better after 1-3 months of psychological guidance accompanied by ARV treatment. Religious aspect obtained improvement before and after recognizing ODHA status. HRQOL on ODHA is based on four aspects such as physics, psychology, mental emotion, and religion and it is already well done after obtaining guidance in health service quality.

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pISSN 2964-2035
eISSN 3025-9258

## Introduction

HIV (*Human Immunodeficiency Virus*) and AIDS (*Acquired Immunodeficiency Syndrome*) are diseases that continue to grow and become global health problems in both developed and developing countries. HIV is caused by HPV (*Human Papilloma Virus*) which enters white blood cells, where HPV damages the structure of white blood cells that function as a defense against infection, resulting in a decrease in the number of white blood cells resulting in a weak immune system and patients are easily exposed to various diseases, then hereinafter this condition is called AIDS (Adhiputra, 2018).

According to data from the *United Nations Programme on* HIV *and* AIDS (UNAIDS) in 2018, there were 36.9 million people with HIV/AIDS. There was a very large increase when compared to 2012, in that year the number of HIV / AIDS cases was still at 34 million cases (UNAIDS, 2018). The increase in HIV prevalence

occurs due to several factors, including demographics or rural environments that provide great potential for HIV transmission, loss of life partner relatives and even being shunned by family, economic, and social challenges after being diagnosed with HIV (Victoria, *et al* 2017).

The transformation of the condition of HIV sufferers into chronic can be handled by increasing the effectiveness of immunological treatment with health-related quality of life programs called *Health-Related Quality of Life* (HRQOL). Quality of life is used to describe the extent to which human needs are met or the perceived level of satisfaction or dissatisfaction of individuals or groups across different aspects of life. It is summarized as an indicator of the level of objective fulfillment of human needs about subjective personal or group perceptions of well-being (Surur *et al*, 2017).

Based on the initial data obtained by the author, namely the low rate of HRQOL in people with HIV/AIDS (ODHA) which has an impact on the long-term life of PLHIV (People with HIV AIDS) itself and the efforts made by the Victory Plus Foundation so that HRWOL in PLHIV increases, the author is interested in researching the phenomenological study of HRQOL in PLHIV covering physical, psychological, mental and religious health.

## Methods

This study used qualitative research methods with a phenomenological approach conducted at the Victory Plus Foundation Yogyakarta from September to October 2019. The number of participants in this qualitative research is not determined by the size of participants using statistical techniques, only determining the estimated number of samples with heterogeneous sample types, namely 6-12 informants. Information is obtained by in-depth interview techniques with informants, namely PLHIV. Data analysis is used through the stages of data reduction, data encoding, and verification.

## Results

Based on the results of research and data analysis as well as the description in the previous discussion, regarding *Health-Related Quality of Life* in PLHIV, it can be concluded as follows; Physical quality is the most influential aspect of the quality of life of PLHIV, where most informants experience varied physical changes within a few years at the beginning of HIV diagnosis. As per the interview excerpt between the researcher and the informant as follows: "I am in stage 3 because it has entered my lungs and I have air entering my extra lungs and I underwent this kind of surgery (informant shows the surgical scar on the right side of the chest). I have many diseases, hehe. Herpes, skin diseases. Here is an example of this. It came out. Yes, herpes. It all came out, miss." (If4). Skin rashes are complaints that are often felt by informants so these complaints cause other impacts that affect the work and activities of informants.

**Table 1**. Characteristics of PLHIV Informants in Yayasan Victory Plus Yogyakarta

| Informant | Age | Gender | Recent Education | Work | Marital Status | Religion | Residence | Long known Status |
|---|---|---|---|---|---|---|---|---|
| 1 | 32 | Woman | Junior High School | Housewives | Marry | Islam | Parent's Home | 9 Years |
| 2 | 33 | Woman | Senior High School | Employee | Marry | Islam | Home | 13 Years |
| 3 | 37 | Man | Diploma | Employee | Unmarried | Catholic | Rent House | 10 Years |
| 4 | 38 | Woman | Diploma | Employee | Marry | Christian | Home | 2 Years |
| 5 | 21 | Man | Senior High School | Student | Unmarried | Islam | Rented | 1 year |
| 6 | 41 | Woman | Junior High School | Employee | Marry | Islam | Home | 8 years |
| 7 | 9 | Woman | Kindergarten | Schoolchildren | Unmarried | Islam | Parent's Home | 9 years |

Of the seven informants, three belonged to the young reproductive age between 20-35 years (If 1, If2, If5), one belonged to the 12-year child (If7) and three belonged to the old reproductive category between 36-49 years (If1, If4, If6). Five informants were female (If1, If2, If4, If6, If7) and two informants

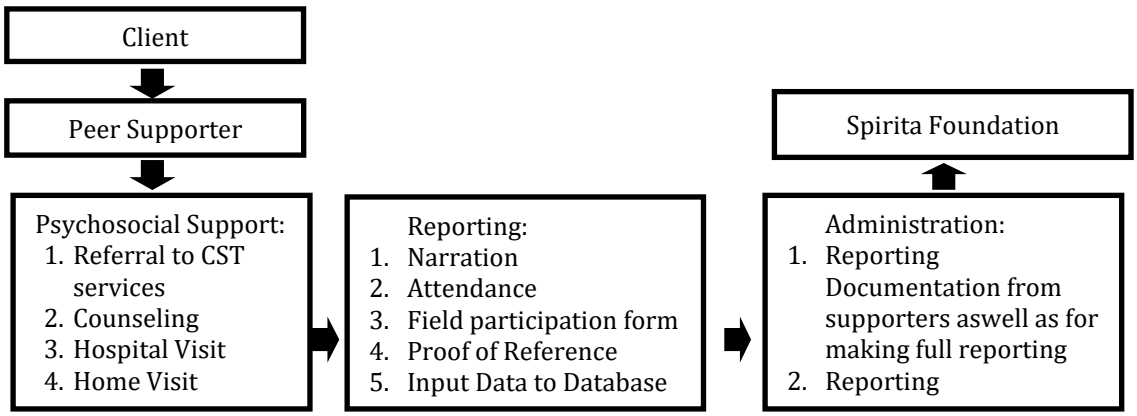
were male (If3, If5). The informant's last education varied, one informant's last education was kindergarten (If7), junior high school (If1), high school two people (If2, If5), and D3 (If3, If4, If6).

The majority of informants work as employees (If2, If3, If4, If6), one informant as a student (If5), one informant as a housewife (If1), and one informant as an elementary school child (If7). Meanwhile, the status of marriage informants varies, five informants have marital status married (If1, If2, If4, If5, and If6), and two people have unmarried marital status (If5, If7). The religious characteristics of informants vary, five religious informants Islam (If1, If2, If5, If6, If7), one informant religious Katolik (If3), and one informant Christian Protestan (If4).

The characteristics of known HIV/AIDS status for a long time in informants vary, two informants know the status of 9 years (If1, If7), If2 knows the status of 10 years, If3 knows the status of 11 years, If4 knows the status of 5 months, If5 knows the status of 1 year, and If6 knows the status of 8 years.

This study has limitations stemming from factors or health conditions of research participants that can decrease. The anticipation that needs to be done is to continue to provide encouragement and encouragement. Another limitation is the involvement of various parties, both research participants and organizers.

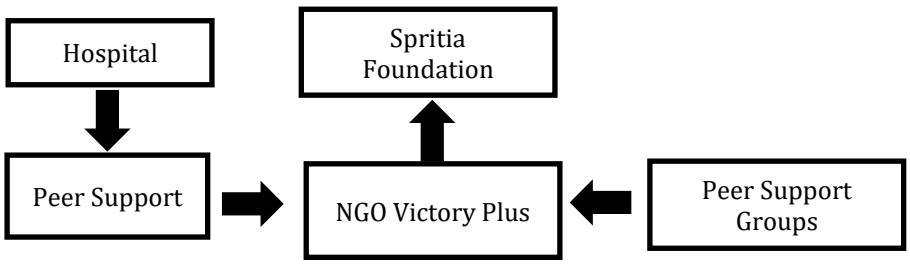
## NGO Workflow Victory Plus




(Source: Victory Plus NGO Data)
**Figure 1.** Victory Plus Workflow

The workflow of the Victory Plus Non-Governmental Organization depicted in the diagram above can be detailed in that what is meant as a client in this case is a person who is detected and positively diagnosed with AIDS. Clients will receive a direct referral from the community integrated with Victory Plus which already has peer supporters to be placed in the Hospital for initial assistance for people newly detected with HIV/AIDS. Peer support is an important part of the process of mentoring positive people to become PLHIV. Meanwhile, the flow of data collection as a report from the NGO Victory Plus to the Spritia Foundation is:

## Victory Plus Foundation Data Collection Flow




(Source: Victory Plus NGO Data)
**Figure 2.** Victory Plus Data Collection

In the data collection process, Victory Plus is a Non-governmental Organization engaged in handling and empowering HIV and AIDS. Through the peer support program conducted by Victory Plus, these counselors and peer supporters are the main basis for collecting data on new people with HIV and AIDS status, most of which are obtained from hospital referrals that have been coordinated with Victory Plus.

## Discussion

### Physical Health

Based on the interviews, it was found that four informants said that their health status was good, and three informants said they were not feeling well. The results of research by Denny et al (2018) stated that most PLHIV is in good physical health status influenced by adherence factors to taking ARVs and continuing to carry out daily activities. This is also in line with research conducted by Victoria *et al* (2017) which found a relationship between CD4 values at the beginning of ARV treatment with the ability to live 1 year of people with HIV AIDS. Informants with several complaints during the interview were influenced by excessive physical activity such as the habit of sleeping late because they were still working or doing activities at night. This follows the research of Izzati et al (2016), in their research found that the level of fatigue in PLHIV affects the physical condition of PLHIV by as much as 46%.

### Psychological

The results of interviews with informants regarding psychological aspects found that the majority of informants experienced depression at the beginning of knowing the status (6 informants) which was shown by anger, crying, no appetite, difficulty sleeping, shutting themselves up, easily anxious, excessive fear, difficulty concentrating, stigma emerged from oneself, despair to the intention to end life. The results of Sulistiani's research (2018) show that participants' responses to their HIV status begin with feelings of sadness followed by denial, distrust, and lack of self-acceptance.

Other psychological symptoms that appear are in the form of sleep disorders and impaired concentration, one informant once attempted suicide by planning to drink insect poison (If5). Wardono's research (2017) states that this psychological response can be followed by an attitude of closing informants from the environment and the surrounding community or community. Other responses that arise are depression and even suicidal ideation. This is consistent with the results of a study conducted by McLeish (2015) where in receiving a positive diagnosis of HIV, some participants in his study experienced various stages of grief before accepting the fact that they were infected with HIV.

### Mental-Emotional

Things that were explored in the mental-emotional aspects of informants found that the majority of informants were able to move normally such as returning to the beginning before knowing the status, at the beginning of knowing the status, mental and emotional conditions could not be controlled, and difficulty working and activities because they could not concentrate properly.

Irawati's research (2015) shows bivariate results between the employment status of PLHIV and the proportion of 1 year-life ability of PLHIV showing that PLHIV who work have a better level of survival ability than PLHIV who do not work or do activities at home. Research in Nepal also concluded that PLHIV who do not work have a 3.5 times greater risk of not adhering to ARV therapy compared to PLHIV who work (Wasti *et al.,* 2012). Similarly, research conducted in Cameroon concluded that there is a significant relationship between work and non-adherence to ARV therapy in PLHIV, where the proportion of PLHIV who work and do not adhere to ARV therapy is 54.5% (Yone *et al.,* 2015).

### Religion

The word religion is a basic word of religion, religion comes from the foreign language religion as a form of noun meaning religion or belief in the existence of a natural force above humans. Religious comes from the word religious which means religious nature inherent in a person (Temongmere, 2012). Religion as one of the character values is described by Mutabazi (2017) as an attitude and behavior that is obedient in carrying out the teachings of the religion adhered to, tolerant of the implementation of worship of other religions, and living in harmony with followers of other religions.

The results of interviews with informants regarding religious aspects found that the majority of informants experienced a drastic increase in worship from before knowing the status of HIV/AIDS compared to after knowing the status. Religious individuals have faith and always surrender to God, this attitude gives an optimistic attitude to oneself so that positive feelings such as happiness, calm, security, and comfort arise (Jalaluddin, 1996 in Adhiputra, 2018).

## Conclusion

Based on the results of research and analysis of data and descriptions in the previous discussion, regarding Health Related Quality of Life in PLHIV, it can be concluded as follows; Physical quality is the most influential aspect of the quality of life for PLWHA, where most of the informants experienced various physical changes in the several years at the start of their HIV diagnosis. Skin rashes are complaints that are often felt by informants so these complaints have other impacts that affect the work and activities of informants. The quality of life of PLWHA is related to psychological and mental-emotional health, namely the presence of fear and difficult self-coping. This has an impact on social activities and irregular lifestyles. Quality of life related to religion is more directed at positive changes in PLWHA who are increasingly obedient to religion which also affects ARV consumption. Conduct in-depth research on effective coping strategies for PLHIV to overcome fear and anxiety. Develop psychological support programs that can be integrated with medical care to improve the mental-emotional health of PLHIV.

## Limitation

This study has limitations stemming from factors or health conditions of research participants which can decrease. The anticipation that needs to be done is to continue to provide enthusiasm and encouragement. Another limitation is the involvement of various parties, both research participants and organizers.

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