

# QUALITY OF MEMBERS OF THE INDONESIAN POSITIVE WOMEN'S ASSOCIATION (IPPI) WHO LIVE WITH HIV/AIDS IN BANDUNG INDONESIA

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## **Abstract**

*Quality of life is an individual's perception of his life in society in the context and existing value systems related to goals, expectations, standards and also defenses against life. Quality of life refers to aspects of physical health, psychological conditions, social relations and the informant's expectations of current life. The research method used is the descriptive qualitative research method. The technique used is by conducting in-depth interviews and documentation studies. Determination of informants using purposive sampling totaling 7 informants. Testing the validity of the data using triangulated sources and techniques, referential adequacy, and persistence of observations. Data analysis techniques by doing data reduction, data display, and also make conclusions. The result showed that women with HIV/AIDS in Ikatan Perempuan Positif Indonesia (IPPI) had a fairly good quality of life. Physical health, psychological aspects and social relations show good results. Environmental aspects of the informants were unable to fulfill their needs due to lack of access to work and lack of skills.*

## **Keyword :**

*Quality of life, Women with HIV/AIDS*

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## **INTRODUCTION**

Indonesia is one of the countries with several social problems, one of the social problems that have an impact on human life is HIV/AIDS. Human Immunodeficiency Virus-Acquired Immune Deficiency Syndrome or hereinafter referred to as HIV/AIDS is one of the infectious diseases that still dominates today. HIV/AIDS is one of the problems in the social and global health sector because this disease is developing in an epidemic. Problems related to HIV/AIDS are ranging from transmission, impact, to handling which is a very complex problem. Based on data obtained from the Ministry of Health of the Republic of Indonesia, it is known that the cumulative number of reported HIV infections up to March 2020 was 640,433 people. Until 2019 the age group that is susceptible to infection is the age of 20-39 years (infodatin [www.kemendes.go.id](http://www.kemendes.go.id)). The number of women infected with HIV is 3,609 people and of that number, as many as 450 women have been detected with AIDS (Ministry of Health, 2020).

West Java province occupies the fourth position with the most HIV sufferers and occupies the 12th position for AIDS sufferers. Regarding the number of HIV infections, West Java Province is the province with the highest number of people with 34,149 people (Ministry of Health, 2020).

Bandung city is one of the areas of West Java Province. In the city of Bandung, the number of people infected with HIV and has entered the AIDS phase is 5,434 people, of which 28.42 percent are women with HIV/AIDS (Bandung City Health

Office, 2020). This number consists of housewives who are infected by their husbands or women who are infected with HIV due to sexual activities and the use of unsterile needles. Based on the results of interviews conducted by researchers also found that most of the women infected with HIV/AIDS were from their husbands.

AIDS is a late discovery of HIV so that the number continues to soar, plus HIV is a problem like an iceberg where there are many cases whose existence has not been revealed (kumparan.com). In 2020, the number of women with HIV/AIDS in the city of Bandung reached 1,544 people with the key population being women who were infected from partners, housewives and commercial sex workers (PSK) (Bandung City Health Office, 2020).

Research conducted by the Mapping Study of HIV/AIDS Key Populations in the City of Bandung states that the number of key populations in the City of Bandung that is most widely mapped is the group of women, both sex workers (FSW) or not. This is one of the reasons that women are the most vulnerable to HIV and AIDS transmission, especially from heterosexual partners. This vulnerability is caused by the gender inequality experienced and the existing economic conditions. This vulnerability will also result in many things, such as a lack of self-acceptance and anxiety about the future that will arise. Vulnerability in transmission will greatly affect the quality of life of people infected with HIV/AIDS or commonly referred to as PLWHA.

Transmission of HIV/AIDS is currently not only limited to people who are

close to free sex or illegal drugs, but can also affect anyone, including housewives, children and even health workers (Ministry of Health, 2020). This means that HIV/AIDS transmission can penetrate all age groups, ranging from small children, teenagers, adults, even to the elderly, be it royalty, workers, unemployed, housewives, students, students, entrepreneurs, and others. This is caused by several behaviors that make the virus spread, such as free sex that does not use contraception, homosexual, lesbian and heterosexual sexual behavior, injection needle users, mother-to-child transmission due to lack of information to the public about the dangers of HIV/AIDS transmission.

The impact of being infected with HIV/AIDS is also not limited to only in the health sector, but covers various fields of human life. These problems will also interfere with the quality of life they live, both in terms of physical, psychological, social and the environment they live in. Many of the cases of women infected with HIV/AIDS have to live their own lives to meet the needs of themselves and their families because their partners have died because they entered the AIDS period. Some cases make it affect the quality of life, both in terms of physical, psychological, social and environmental living with HIV/AIDS.

Quality of life itself is a new concept that comes from "General welfare". The initial definition of quality of life was given by the World Health Organization (WHO) which relates to the health sector, namely "not only the absence

of infinity and the disease but also a state of physical, mental and social well being" (WHOQOL, 1997:15). This implies that the quality of life is not only the presence of weakness and disease but also from the aspect of physical, psychological, social and environmental relationships.

Vulnerability of HIV/AIDS transmission to women, especially housewives, are vulnerable to HIV/AIDS infection due to low bargaining power and negotiation in sexual relations. Based on the 2016 UN AIDS agency report or UNAIDS, which states that more than 1.7 million women in Asia are living with HIV, and 90% of them are infected by their husbands or sexual partners.

The conditions and various problems faced by PLWHA make them need services throughout their lives. Services for PLWHA can be obtained from various service systems such as health facilities or Non-Governmental Organizations (NGOs) as well as communities or organizations, even now Indonesia has a network that cares about HIV/AIDS. The network that reaches out and helps in mentoring and empowering women with HIV/AIDS to have a better life, the network is the Indonesian Positive Women's Association (IPPI). IPPI is a national network initiated by and for women living with and affected by HIV which was established on June 17, 2006 in Jakarta.

IPPI was formed with the vision of empowering women living with HIV and affected women to achieve an equal and prosperous life in health, social, educational and economic aspects. IPPI's

mission is also to strengthen women living with HIV and the ability of affected women to empower themselves and other women in the aspects of health, social, education, and economic quality through advocacy, funding, and improving skills to achieve their welfare.

Women living with HIV and women affected are women who are infected with HIV due to infection from a partner or because of unhealthy sex activities. The IPPI profile describes that the IPPI has covered 25 provinces and is led by 25 women as provincial coordinators.

One of the IPPI developments is located in Bandung City, West Java, which has a reach of 106 people and who are active members of approximately 25 women as stated by one of the IPPI West Java provincial coordinators who was met.

The quality of women living with HIV/AIDS who are members of the IPPI may vary. IPPI helps women with HIV/AIDS to rise up and be able to empower themselves so that they want to be open and open status to their families or to people who, according to women with HIV/AIDS, need to know, the community also thinks that PLWHA is someone who is very dangerous and should be avoided because of the disease that causes HIV/AIDS. suffers, therefore most of those who are already infected with HIV or have become PLWHA will close their status as PLWHA to their environment.

The alienation felt by PLWHA who are members of the IPPI from the social and family environment has made the quality of life of PLWHA decrease drastically. PLWHA sometimes still find it difficult to

accept that they are infected with the HIV/AIDS virus, because they think that they are worried about their future and are afraid to leave their children and the future, even more fearful is premature death.

Another impact of HIV apart from the physical aspect is also the psychological aspect of women living with HIV/AIDS who feel down and affect the social relationships of PLWHA with other people. This affects the environment of women with HIV/AIDS so that the quality of PLWHA can decrease. The quality of life of PLWHA makes the lives of PLWHA greatly affected in various aspects.

Social work is one of the professions that has an important role in dealing with the problems of people living with HIV/AIDS (PLWHA). Social work is one of the professions where they try to strengthen the social functioning of individuals, groups or communities who have social problems, one of which is PLWHA. Social work is a professional activity that helps individuals, groups, or communities to improve and restore their ability to function socially to create social conditions that support these goals (Zastrow in Fahrudin, 2014).

This encourages researchers to want to understand more deeply about social work with HIV/AIDS by examining the Quality of Life of Women with HIV/AIDS in the Indonesian Positive Women's Association (IPPI) Bandung City.

The aspects that will be examined from the quality of life in this study are physical health, psychological conditions, social and environmental relationships of PLWHA who are members of the

Indonesian Positive Women's Association (IPPI) Bandung City.

The formulation of the problem from this research include (1) What are the characteristics of women with HIV/AIDS?; (2) How is the physical health of women living with HIV/AIDS?; (3) What is the Psychological Condition of Women with HIV/AIDS?; (4) How are Women's Social Relationships with HIV/AIDS?; and (5) How is the environment of women living with HIV/AIDS? This is what will be examined in this study on women with HIV/AIDS who are members of the Bandung City IPPI.

## RESEARCH METHOD

This study uses a qualitative method with a descriptive approach. Qualitative research is research that intends to understand the phenomena of what is experienced by research subjects such as behavior, perceptions, motivations, actions, etc., holistically and by means of descriptions in the form of words and language in a special natural context and by utilizing various methods. natural (Lexy J. Moleong 2017). The qualitative approach is to examine more deeply the research problem and obtain accurate data in the field about the quality of life. The descriptive approach aims to make a description of the facts found and the relationship between the phenomena studied in the study.

During this pandemic, research data were obtained from in-depth interviews and documentation studies by applying health protocols to 4 women with HIV/AIDS who were members of the IPPI regarding the

quality of life of women with HIV/AIDS. The implementation of data collection was carried out by researchers both directly and online. Informants were recruited using a purposive technique. The use of this technique is in line with the aim of the researcher, which focuses on women with HIV/AIDS who are active members of the Bandung City IPPI with different backgrounds. The researcher also conducted interviews with three IPPI peer counselors, and one family member of a woman living with HIV/AIDS to support the data obtained.

Data analysis was carried out by researchers by collecting data in the field and making a summary of the data that had been obtained. Then the researcher will present the data from the data that has been grouped to then draw conclusions. This is based on the data analysis technique proposed by Miles and Huberman who stated that qualitative data analysis was carried out by (1) Data reduction (data reduction); (2) Data display (presentation of data); and (3) Conclusion (drawing conclusions) (Sugiyono, 2014).

## RESULTS

The results of research conducted by researchers regarding the Quality of Life of Women with HIV/AIDS who are members of the Bandung City IPPI have various different qualities of life. The four informants were chosen because they were considered capable of providing information about the quality of life. The four selected informants have different backgrounds on the causes of HIV/AIDS so that accurate data can be obtained

regarding the quality of life of women living with HIV/AIDS.

The results obtained by this researcher came from the results of interviews and documentation studies to informants, namely women with HIV/AIDS, companions, and female relatives with HIV/AIDS. The results obtained in accordance with the formulation of the problem, namely regarding the characteristics of women with HIV/AIDS, physical health, psychological conditions, social and environmental relationships of women with HIV/AIDS who are members of the Bandung City IPPI.

**1. Characteristics of Women with HIV/AIDS**

The characteristics of women with HIV/AIDS can be described in the following table:

Table 1 Characteristics of Women with HIV/AIDS

| Nama | Usia | Status Pernikahan | Pekerjan          | Tahun HIV |
|------|------|-------------------|-------------------|-----------|
| A    | 39   | Cerai mati        | Ojek, Parkit, ART | 2011      |
| T    | 38   | Cerai mati        | Vouunteer IPPI    | 2018      |
| R    | 26   | Cerai             | Pemandu lagu      | 2017      |
| S    | 39   | Cerai mati        | Pendamping Female | 2013      |

Table 1 shows that women with HIV/AIDS who are members of the Bandung City IPPI differ in the length of time they have had HIV/AIDS status. The characteristics of each informant will be further elaborated in the following explanation:

a. Age

The four informants were of different ages. Informant A is 39 years old,

informant T is 38 years old, informant R is 26 years old and informant S is 39 years old. The four informants have different age backgrounds but are still said to be productive.

b. Religion

The religion of all the informants interviewed by the researcher is Islam. The primary informants of this study stated that after being infected with HIV they surrendered everything to God and increased their worship and were grateful that they were still alive today and were able to rise, although sometimes there is still a feeling of disapproval of the word disappointed but diverted to worship and gratitude activities.

c. Education

The average education of the informants is SMA. This affects knowledge of HIV/AIDS so that they are infected with HIV/AIDS due to the ignorance of female informants with HIV/AIDS.

d. Marital Status

The marital status of the four main informants, namely A, T, and S, is divorced, while R is divorced so that the status of the four main informants becomes single parents because they live together with their children. All informants who are divorced know their HIV status when their husband's condition enters the AIDS phase, which makes the informants perform a VCT examination and find out that HIV/AIDS is indicated. Meanwhile, R found out about this when R's immune condition began to weaken and found out after checking with her husband and then choosing to divorce.

e. Profession

The work of the four main informants can be said to be odd. Informant A who becomes a motorcycle taxi driver, parking attendant, and sometimes also a household assistant by cleaning the house of friends or neighbors who need his services. Informant R became a song guide at a karaoke place in Bandung. H and S, who were more involved, became IPPI volunteers where they were trusted to accompany friends who had just joined the IPPI.

Informants A and R have not dared to look for another permanent job even though there is a desire due to their fear of not having an open status. Meanwhile, T and S are comfortable with their current jobs because they are in the same environment as PLWHA, so they are comfortable doing their jobs.

f. Long time infected with HIV

A and S are women with HIV/AIDS due to being infected by their husbands, but S's condition is slightly different because they know this when they enter their gestational age. R himself contracted HIV due to risky behavior, namely as a commercial sex worker. T is a woman with HIV / AIDS due to risky behavior by using injections alternately with her husband since dating.

A learned that A had HIV/AIDS since 2011 and joined the IPPI eight months after A tested positive. Informant T has known his condition since 2018. Informant A has known the condition of HIV since 2017 while Informant S has been since 2013. The four informants have different times and the informant who has the closest time is T, which is five years, while the longest period is ten. year.

## 2. Physical Health

Physical health in this case is a condition that includes illness and anxiety, sleep and rest, energy and fatigue, mobility, daily activities, dependence on drugs and work capacity.

a. Perceived Physical Health Conditions

First, women living with HIV/AIDS have the energy to carry out their daily activities and work for which they are responsible. The informants felt that there was no influence from HIV/AIDS that hindered their energy. Fatigue that is felt in their daily lives is also caused by work and busy activities, especially for women with HIV/AIDS who work odd jobs.

Second, female informants with HIV/AIDS felt sick and uncomfortable in the early days of taking ARVs, such as dizziness, nausea, diarrhea and skin rashes. Another thing that is felt is that informants are more susceptible to diseases such as flu and coughs which are prone to longer healing times than ordinary people. Informants who do not have co-morbidities only feel pain from the effects of the drugs used and congenital diseases such as ulcers and asthma.

Third, the condition of the body and shape is not too affected, it's just that the condition of the body experienced a drastic weight loss in the early days of HIV and before taking ARVs. Condition and body shape is said to be good.

b. Ability to carry out activities

First, the mobility ability of women living with HIV/AIDS. Informants carry out mobility such as moving to work, on vacation or spending time doing homework. Female informants with

HIV/AIDS do not experience obstacles in carrying out daily mobility due to their supportive physical health.

Second, self-care for women with HIV/AIDS. Informants Women with HIV/AIDS also take care of themselves by practicing a healthy lifestyle, although from the four informants there are still three informants who do it except for informant R. This is done by taking medicine, vitamins, doing skin care for rashes and doing other self-care that supports health physical.

Third, sleep and rest. Some female informants with HIV/AIDS experience sleep disturbances so that they feel less time to rest. This happens because of the burden of thought that is felt and the effects of drugs that cause hallucinations. Sleep disturbances sometimes occur several times, but are not so disturbing.

Fourth, the ability to work and improve skills. Female informants with HIV/AIDS can do work according to their capacity but have not been able to improve their skills because there is no forum to improve their skills so that some informants have temporary jobs.

c. Drug use

Female informants with HIV/AIDS consume ARV drugs regularly, once a day. ARV drugs are also supported by taking vitamins and a healthy lifestyle. Informants also experienced different effects regarding the drug, including nausea, dizziness, skin rash, diarrhea and weight loss during the initial period of use. The effect gradually diminishes after long-term use.

### 3. Psychological Aspect

The psychological aspect is related to the mental state of the individual. The mental state refers to whether or not the individual is able to adapt to various developmental demands according to his abilities.

a. Feelings about the current state

The first is about positive feelings. Informants have positive feelings to continue to rise and live life because they see the family and people closest to the informant. The informants also feel grateful for being able to rise to the current state of the informants.

Second, about negative feelings. Female informants with HIV/AIDS feel hopeless and sad about the existence of HIV/AIDS in the informants. Informants also feel that they have failed to become parents because with HIV the informant has not been able to meet their needs and get a permanent job. These feelings arise when the informant feels tired and sick. The informant also imagined about the death that would come to the informant.

b. Ability to concentrate, remember and make decisions

First, the ability to concentrate, remember and make decisions. Informants make decisions by discussing with their families or considering the good and bad decisions that will be taken. Some of the informants experienced a decrease in memory and concentration, but of the four informants, only one had a decrease in concentration and one person experienced a decrease in the ability to remember. This is also due to another factor, namely age.

Second, spirituality and belief. The informant considers that HIV/AIDS in the



informant is a destiny that must be lived. The female informant with HIV/AIDS felt angry at God when she was initially identified as having HIV/AIDS. But now the informant is grateful to be alive until now and is getting closer to God.

Third, Self Esteem (Self-esteem). Informants now have self-respect and want to live a long life. Self-esteem is done by being grateful and maintaining personal health by implementing a healthy lifestyle. Informants who work in the community also feel proud and make themselves role models that PLWHA can carry out activities like humans in general.

Fourth, informants have good knowledge of HIV/AIDS. This knowledge includes information about the causes, modes of transmission, and other information that supports the lives of women living with HIV/AIDS. The information was obtained from hospitals, doctors, peer counselors, and IPPI.

c. Behavioral tendencies

Female informants with HIV/AIDS tend to spend time or activities with other PLWHA because they feel comfortable and open. However, some informants did not close their relationship with a certain number of people other than PLWHA. This is because the informant is still afraid that other people will know the informant's HIV status.

#### 4. Aspects of Social Relations

Social relationship is a relationship between two or more individuals where the behavior of the individual influences, changes or improves the behavior of other individuals. Based on the results of

interviews and documentation studies, the following results were obtained:

a. Interaction of women with HIV/AIDS with other people

Informants are open about the status of the closest people such as family or partners. Some of the informants were also open about their status to their neighbors, such as informant A. The relationship between female informants and HIV/AIDS can be said to be good with their families. The family has accepted because they already know the mode of transmission even though at first there was refusal.

Relationship with IPPI Friends. Female informants with HIV/AIDS relate well to their IPPI colleagues. Informants and IPPI colleagues gave each other support during joint activities. In addition, informants will also share information both directly and online via WhatsApp groups.

b. Social Support (the availability of people around to provide assistance)

Informants received assistance from family and friends from IPPI. Social support provided by the family in the form of support and also school fees for children from female informants with HIV/AIDS. Meanwhile, the support provided by IPPI partners is in the form of support and information on matters that support the lives of women living with HIV/AIDS.

c. Involvement of leisure activities

Women with HIV/AIDS fill their spare time by cleaning the house or taking vacations. This is done simultaneously with family and partners. Female informants with HIV/AIDS also spend a lot of time with their children because female

informants with HIV/AIDS are single parents.

### **5. Aspects of the Environmental Dimension**

The environment in terms of quality of life is the individual's residence, including the circumstances, the availability of a place to live to carry out all life activities, including facilities and infrastructure that can support life. The results of the research include:

#### **a. Physical environment safety**

First, the fulfillment of family needs. Female informants with HIV/AIDS are single parents so they rely on themselves to meet their needs. Female informants with HIV/AIDS experience obstacles in meeting their needs due to precarious work. This is because female informants with HIV/AIDS do not have the skills to have a job so that the fulfillment of their needs is hampered.

Second, the availability of special facilities. Female informants with HIV/AIDS do not have special treatment in their families because they already know about HIV/AIDS. Informants mingled in family activities and were not isolated. However, in receiving health facilities, some informants received special treatment such as more sterilized and prioritized equipment, although not all of them received this treatment.

#### **b. Availability of access to information and transportation**

Female informants with HIV/AIDS have easy access to information. The information includes healthy lifestyles, treatment, and other health services that can support the lives of women living with HIV/AIDS.

Transportation is also accessible for women living with HIV/AIDS. Informants access transportation for their own daily activities. Access that can be used is relatives or family who will lend their transportation needs or access existing public transportation.

#### **c. Ketersediaan sumber penghasilan**

Female informants with HIV/AIDS have less sources of income. This source of income cannot meet the needs because the informant does not yet have a fixed source of income. This happened because the HIV status of women with HIV/AIDS made the informants think they could not access sources of income other than in the community. Informants who work in the community with this source of income are still unable to meet other needs other than in the community. There are also informants who work by engaging in risky behavior so that they need access to other sources of income.

#### **d. Availability of health services**

Informants feel that health services are well accessible. Health services include hospitals or health centers. The female informant with HIV/AIDS did an examination at the same hospital and doctor since the initial examination and was declared HIV/AIDS. The examinations carried out are such as routine weight checks, psychiatric consultations, drugs or other examinations such as skin and teeth. Inspections are carried out routinely once a month.

The quantity of health services has also been provided in every hospital. Both specifically for PLWHA and in general. Access to drugs is carried out in the same

hospital as the health examination. Examination and medicine can be accessed for free.

## 6. Hope Informants

Informan perempuan dengan HIV/AIDS memiliki harapan untuk memiliki umur yang panjang dan memiliki kesehatan yang baik. Harapan lain yaitu perempuan dengan HIV/AIDS dapat menerima peningkatan keterampilan sehingga dapat memiliki pekerjaan yang tetap dan dapat memenuhi kebutuhan sehari-hari.

## DISCUSSION

Female informants with HIV/AIDS have hope to have a long life and have good health. Another hope is that women with HIV/AIDS can receive increased skills so that they can have permanent jobs and can meet their daily needs.

### 1. Karakteristik Informan

Based on the discussion of the research results above, the characteristics of female informants with HIV/AIDS can be concluded as follows:

- a. Women with HIV/AIDS are caused by the infection of their husbands, the use of unsterile needles and during pregnancy.
- b. Women with HIV/AIDS have a productive age
- c. Women living with HIV/AIDS believe that HIV/AIDS is destiny.
- d. Women living with HIV/AIDS do not have permanent jobs and only rely on work in the community.

### 1. Aspects of Physical Health

Physical health affects an individual's quality of life related to the components of energy and fatigue, pain and discomfort, body shape and condition, use of drugs and other components related to a person's physique (WHO, 2012).

#### a. Perceived physical health

The first concerns energy and fatigue. Energy is the ability to do work or power that can be used by individuals to carry out various process activities (KBBI, 2020). According to the informant, the energy possessed is sufficient to carry out activities in daily life and does not experience obstacles. In addition, the feeling of fatigue that is felt is not caused by HIV/AIDS but by the work of women living with HIV/AIDS itself and the effects of ARV drugs. This is relevant to the research conducted by Hartiah Haroen, et al (2015) regarding the quality of life of women with AIDS and their partners with AIDS in Bandung Regency which stated that the HIV/AIDS condition did not feel physical symptoms, only felt tired quickly due to the effects of drugs such as diarrhea and nausea.

Second, the pain and discomfort suffered by female informants with HIV/AIDS was due to the effects of the drug, causing nausea, diarrhea, pain, and discomfort. In addition, female informants with HIV/AIDS who do not have comorbidities do not experience any obstacles other than congenital diseases such as ulcers or asthma suffered by the informants. The results of research from Farah Rizki Deskia (2020) state that people with HIV/AIDS have a high risk of comorbidities with HIV/AIDS, which makes

them uncomfortable. Based on the results of the study, half of the respondents living with HIV/AIDS had co-morbidities with tuberculosis. This is different from the current research conducted by researchers where women with HIV/AIDS do not yet have physical comorbidities.

b. Ability to carry out activities

First, mobility capabilities. Mobility is an individual's ability to move easily, freely and regularly to achieve a goal, namely to fulfill his life needs both independently and with the help of other people or tools (Widuri, 2010). Based on the research results, female informants with HIV/AIDS can carry out mobility in order to meet needs such as work, spending time on vacation, and with their families by doing activities at home in the daily lives of female informants with HIV/AIDS.

Second self care. Self-care is one of the basic human abilities in meeting their needs in order to maintain their life, health, and well-being in accordance with their health conditions. (Dermawan & Rusdi, 2013). Informants with HIV/AIDS carry out self-care by maintaining a healthy lifestyle, taking ARV drugs regularly, and carrying out health-supporting treatments such as routine check-ups and skin care. The results of previous research by Intan Tri Dini Lestari (2016) are relevant to the results of the current study where the results of the study stated that self-care carried out by PLWHA resulted in consuming drugs outside of prescriptions, getting ARVs, besides that there were good efforts by coming to services. health to deal with complaints or symptoms that are felt and do not forget to take ARV drugs.

Third, sleep and rest. Based on the results of the study, female informants with HIV/AIDS experienced sleep disturbances so that they disrupted the informants' rest time. This happened because of the effects of ARV drugs or the psychological condition of the informants. The disorder does not appear all the time but at certain times such as when you are sick or feeling depressed. This is relevant to a study conducted by Juli Andri (2020) which stated that some cases of HIV/AIDS sufferers were unable to rest properly due to itching, fatigue and other drug effects.

Fourth, the ability to work and improve skills. Based on the results of the research, the four informants have good work skills in accordance with their current work. However, they have not been able to improve skills other than work in the community. This makes some informants still do risky jobs and do not have permanent jobs. Based on a case study by Dewi Lestari (2013), it is stated that most housewives living with HIV/AIDS have jobs as volunteers (volunteers) and employees in an NGO that handles HIV/AIDS with monthly payments of approximately Rp. 300,000 – Rp. 500,000 per month. make satisfaction in the ability of working housewives low.

c. Drug use

Based on the results of the research, the use of drugs was carried out routinely by the informants once a day with the support of vitamins, vitamin drinks and a healthy lifestyle. The effects of drugs felt by the informants were also different, including nausea, diarrhea, dizziness, rash, and others. The results of research by Linlin

Lindayani (2016) stated that people with HIV/AIDS had a better physical condition when using or consuming ARV drugs on a regular basis than people with HIV/AIDS who did not use ARV drugs or did not consume them regularly.

## **2. Psychological Aspect**

Psychological aspects, namely the mental state of the individual that leads to whether or not the individual is able to adapt to various developmental demands according to his abilities, both demands from within and from outside the individual..

### **a. Feelings about the current state**

Feelings about current conditions are related to positive and negative feelings from female informants with HIV/AIDS. The positive feelings of the informants include gratitude and pleasure because they have gone through a period of depression and have been able to rise to this day and the willingness to fight. While the negative feelings of the informant include feelings of sadness, anxiety and feeling useless in life since being declared positive. This happens a lot in the early identification of HIV.

This is relevant to the results of research by Ade Sasha Triana (2017) where people with HIV/AIDS have positive feelings which are dominated by feelings of pleasure caused by the presence of a partner, childhood, gratitude, worship, and also family understanding of the condition of people with HIV. HIV/AIDS. As well as negative feelings include feelings of sadness, anxiety about health and problems with family needs.

Ability to think

The ability to think is a condition that lies in the relationship between the parts of knowledge that exist within a person and is controlled by reason. The ability to concentrate, remember and make decisions is one of the abilities in thinking (Riyantono, 2010). In this case, the informant experienced a decrease in the ability to concentrate and remember, but only happened to a few informants. This is also due to the age factor of the age of 40 years. Informants make decisions by sharing their opinions with their families or by considering themselves.

This is relevant to a meta-analysis that reviewed 123 research articles which reported that the condition of HIV/AIDS affects cognitive function where it makes memory and concentration abilities of people living with HIV decrease, although the mechanism cannot be clearly explained. Symptoms that appear are also gradual and slow and require further research on the cognitive abilities of PLWHA (pph.atmaja.ac.id, 2020)

Second, spirituality and belief. Based on the results of the research, female informants with HIV/AIDS assume that life today is destiny and must be lived with gratitude, so it is necessary to approach God even though at first there is rejection. This is relevant to research conducted by I Gede Meyantara Eka, et al, which states that the level of spirituality in PLWHA is directly proportional to the quality of life of PLWHA which means that PLWHA's spirituality can help the rise of PLWHA in life.

Third, self-esteem (self-esteem). Self-esteem is a comprehensive assessment

dimension of the self. Based on the results of research, female informants with HIV/AIDS can respect themselves and evaluate themselves in a positive way (Santrock in Desmita, 2012). Regarding self-esteem, the informant feels grateful and respects himself by adopting a healthy lifestyle and making himself a role model in the current community.

Fourth, knowledge about HIV/AIDS. Based on the research results, female informants with HIV/AIDS have sufficient knowledge about HIV/AIDS to support current life. This knowledge includes prevention and ways of transmitting HIV, healthy lifestyles, and others. This knowledge was obtained from Google, or IPPI seminars and from the PLWHA community. In a study conducted by Juli Andri (2020) also stated that PLWHA had sufficient knowledge about HIV/AIDS when HIV was identified.

a. Tendency to think (Conative Aspect)

Based on the results of research, informants tend to work together with fellow PLWHA because they feel comfortable and can be more open. In addition, the informant was also identified at the early stage of HIV that tended to behave negatively, such as wanting to commit suicide, despair, and slumping, but then after awakening the informant had a tendency to have positive behavior by feeling that he wanted to continue to struggle. Although there are some informants who still carry out risky behavior.

3. Aspects of Social Relations

The informant's social relationship with women with HIV/AIDS based on

good research results. The family can accept the HIV condition that is in the informant. the informant is also only open to the closest person or family who lives in the same house as the informant. although at the beginning it was not acceptable but over time the condition was accepted well. some informants are also open to neighbors or partners about HIV status.

The informant's relationship with IPPI colleagues, both women with HIV/AIDS or their companions, was also considered good and very close because the informants felt they had the same fate, so they were more comfortable and open. The relationships that have been established are carried out both online and in person at IPPI activities or activities of PLWHA.

Female informants with HIV/AIDS also have support from their families and IPPI colleagues. The support is in the form of advice, attention, finance, and also the information needed by women living with HIV/AIDS. Support is also in the form of supervision in the use of drugs. This is relevant to the research conducted by Alva Cherry Mustamu, et al regarding the relationship between family support and quality of life in people with HIV/AIDS which states that family support is needed to encourage the success of PLWHA treatment where the family has a role to monitor and supervise PLWHA in examination and use. medicine and provide encouragement to PLWHA.

Informants also have free time that will be spent with activities together with the closest people such as family, spouse, or children. This is done routinely by

informants when they have free time both outside and inside the informant's house.

#### **4. Environmental Aspect**

First, the fulfillment of the family needs of female informants with HIV/AIDS based on the results of the study could not be fulfilled optimally and experienced several obstacles. This happened because the informant was a single parent and did not have a good source of income. The fulfillment of these needs has not been met, especially in school fees even though they have been assisted by existing families.

Second, female informants with HIV/AIDS do not receive special facilities in the family, but in terms of health, the informants receive special facilities for the convenience of others who use health facilities and for the sake of the informants themselves who are vulnerable to disease transmission. These facilities are in the form of a special examination room for PLWHA, as well as in terms of services. However, this does not mean that informants are excluded. Based on the results of research by Rialeke Burhan (2013) also stated that the government has provided several health facilities at special hospitals for HIV examinations such as VCT, CD4 examinations, and other necessary examinations.

Third, informants also easily access information and transportation. Informants access information directly through peer assistants, doctors, hospitals or colleagues from IPPI. Indirectly, the informant received information from Google and other online information. Transportation is also accessed privately by the informant's

private vehicle. Informants can also easily access online and public transportation easily if needed.

Fourth, source of income. Informants have not been able to optimally access sources of income due to ignorance and also lack of skills. Informants rely on sources of income from the community which can be said to be limited so that some informants do not have permanent jobs and are still doing risky jobs. This is relevant to Fanny Farhani's research, Amelia Arman (2017) which states that stigma and discrimination are the main causes of PLWHA in the city of Bandung not getting decent work and fulfilling the terms of PLWHA in getting a job has not been fully implemented.

Fifth, the availability of health services. The health services received by the informants can be accessed properly. Currently, there are many hospitals and health centers that serve PLWHA and several hospitals have provided special examination services for PLWHA. These services include routine examinations, treatment, as well as tests related to HIV such as VCT, CD4 cells, and ARV therapy. The availability of health services is relevant to research conducted by Rialeke Burhan (2013) which states that there is a stigma on the use of services for people with HIV/AIDS but the availability or activities of care, support, and treatment (PDP) for PLWHA can be obtained in hospitals, health centers, and places that have been appointed by the government. The city of Bandung itself has 17 health services that provide HIV tests, eight health facilities that provide PDP, and others.

## 5. Problem Analysis

Based on the results of the analysis of the research results from the characteristics of the informants to the expectations of the informants, it can be seen that women with HIV/AIDS have a different quality of life when living with HIV/AIDS. Analysis of the problem can be described as follows:

### a. Physical Health Aspect

Aspects of physical health possessed by female informants with HIV/AIDS can be said to have good quality. Informants can have a physical condition that feels good by having energy and a sense of comfort towards the informant's physical condition. Although some of the informants had congenital ailments such as ulcers and asthma, this did not become an obstacle. Informants also have the ability to carry out daily activities well. However, female informants with HIV/AIDS experienced difficulties in sleeping and resting because the four informants sometimes experienced insomnia due to thoughts or the effects of ARV drugs they were taking. Informants also use ARV drugs to support good health and regularly at all times even though they receive effects such as diarrhea, nausea, itching and rash at the beginning of drug adjustment..

### b. Psychological conditions

The psychological condition of the four informants has a fairly good quality where the informants have the ability to think and make decisions by considering and sharing with their families. Informants have positive feelings to continue to rise and improve the lives of informants. Although the informant had negative feelings such as disappointed, sad and felt

useless at the beginning of being identified with HIV. Informants also have the ability to concentrate and remember even though it is reduced due to age and the many burdens to think about. Informants also have good spirituality and self-esteem. The informant assumes that what happened to the informant is destiny and will undergo it. Informants also give self-esteem to the informant and accept the current condition of the informant. Informants also have sufficient knowledge about HIV/AIDS to support the lives of informants.

### c. Social Relations

The four informants have good relationships with their family and friends with IPPI. Informants are accepted by the family and receive support, support and assistance from the family. Even though at the beginning of HIV/AIDS, the family felt shock and did not accept it because they did not know about the spread of the HIV virus. However, the current condition of the informant's family supports the informant's life. The informants also received support from their families in the form of support and several informants received financial assistance for the school fees of the informants' children. This also applies to the relationship between informants and IPPI partners. family or IPPI in social relations. So that it helps the quality of life of the informant to increase in the aspect of social relations.

### d. Environmental

Based on the results of research on the quality of life of women living with HIV/AIDS in environmental aspects,



informants have the availability of special facilities such as personal equipment and hospital services specifically for PLWHA. Informants also have access to the information and transportation needed to support the lives of women living with HIV/AIDS. Informants can also access treatment well. The physical security of the informants is also fairly good, although there are obstacles in meeting needs because of the irregular jobs that some of the informants have. This is also felt by several informants who already have permanent jobs. So that it becomes an urgent problem on the quality of life of women living with HIV/AIDS.

Based on the explanation above, it can be concluded that the problems experienced by female informants with HIV/AIDS are as follows:

- a. Informants had difficulty sleeping and resting due to thoughts and effects of ARV drugs.
- b. The lack of fulfillment of needs is due to the role of women living with HIV/AIDS as single parents.
- c. Lack of access to work other than in the IPPI community or the HIV/AIDS community so that women living with HIV/AIDS have precarious jobs.
- d. Lack of skills possessed by women with HIV/AIDS so that it is not yet possible to work independently.
- e. The empowerment program by the IPPI Department of Economics is in the development stage so there is no training on entrepreneurship for women living with HIV/AIDS.

## 6. Needs Analysis

Based on the problem analysis, the problem analysis that has been carried out on the results of the research on the quality of life of women living with HIV/AIDS who are members of the IPPI and the analysis of the needs of women living with HIV/AIDS.

### a. Skills and Knowledge Training

Skills training is needed by women living with HIV/AIDS to give women living with HIV/AIDS the opportunity to earn their own source of income. This is done to support the fulfillment of the needs of women living with HIV/AIDS. The intended knowledge is about knowledge of the rights of PLWHA so that women with HIV/AIDS can be confident in finding sources of income other than in the community.

### b. Motivation and support for problem solving

Women with HIV/AIDS need motivation to leave work with risky behavior. In addition, women living with HIV/AIDS need motivation to find work so that they do not only rely on the community and can meet their needs. This was done because some of the informants lacked confidence in finding work outside the community with the informant's condition.

### c. Access to source system

The source that can be utilized is the Bandung City Positive Association, which is a place for women living with HIV/AIDS to be empowered. Based on the results of research, women with HIV/AIDS often participate in training activities held by IPPI, but not much is about economic development because most of them are about knowledge about HIV/AIDS and

other knowledge related to HIV/AIDS in the form of seminars. This has not been done because the IPPI Department of Economic Empowerment is still in the development stage. So there is no training program aimed at economic empowerment for women living with HIV/AIDS.

### **7. Analysis of the source system**

The source system according to Siporin in Abu Huraerah, (2011) classifies the source system as follows::

#### **1. Informant or natural source system**

Informal resource systems can be in the form of family, friends, neighbors or other people in providing support. The source system can also be in the form of support and motivation for the quality of life of women living with HIV/AIDS. Based on the results of the research, the informants received informal support from their younger siblings, children, neighbors and friends who wanted to help informants. The support is in the form of motivation, attention, support and the provision of other assistance such as money for needs.

#### **2. Formal sourcing system**

The formal source system is a source system that can be accessed by the informant when the informant is a member of the source. Based on the results of the research, the source system that can be accessed is the Indonesian Positive Women's Association and the HIV/AIDS peer community in Bandung. The support or resources provided are by providing knowledge and training by departments within the Indonesian Positive Women's Association that can be accessed to support the quality of life of women living with HIV/AIDS.

#### **3. 3. Community resource system**

Community resource system is a resource system that can be accessed by everyone and is general in nature. This resource system is an institution established by the government and the private sector that can provide services, especially to women with HIV/AIDS. Source systems that can be accessed by women living with HIV/AIDS are the Bandung City AIDS Commission, Hospitals, and also other institutions that can be used related to women living with HIV/AIDS.

### **CONCLUSION**

The quality of life of a person is different, which in this case is the quality of life of women living with HIV/AIDS. The quality of life is based on aspects of physical health, psychological conditions, social relationships, and also the environment. Each individual has a different quality of life where each individual wants a good quality of life as well as women with HIV/AIDS. Women with HIV/AIDS often receive the effects of significant physical changes due to HIV. In addition, the psychological condition of women with HIV/AIDS will also deteriorate due to the identification of HIV which will later affect the social relations of women with HIV and other people as well as changes in the environment of women with HIV/AIDS itself. Women with HIV/AIDS in meeting their needs experience obstacles due to unstable jobs and uncertain incomes. This makes environmental conditions in the aspect of

the physical environment, namely the fulfillment of needs and access to work.

The quality of life of women with HIV/AIDS who are members of the Bandung City IPPI based on research results show that women with HIV/AIDS experience problems such as in the physical health aspect, namely difficulty sleeping, in the environmental aspect, namely the inhibition of meeting needs and access to work or sources of income. Lack of access to work is due to the lack of skills of women living with HIV/AIDS and lack of motivation to dare to try to find a permanent job or increase their income.

Based on the results of research, many women with HIV/AIDS focus on physical health conditions so that they apply a healthy lifestyle and also pay attention to psychological aspects.

The main cause of not easy access to work is due to the lack of skills of women living with HIV/AIDS. Although the existing resource system at IPPI can be utilized by women living with HIV/AIDS.

This provides a description that women living with HIV/AIDS have needs regarding skills and knowledge enhancement, motivation and support as well as access to resource systems. The source systems that can be accessed are KPA, IPPI, hospitals, and access to other source systems so that women with HIV/AIDS need sources that can support existing problems.

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