

## **Peaceful End Of Life Of Aids Patients In The Group Support Peers (Kds) Kediri City**

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### **ABSTRACT**

HIV infects white blood cells which causes a decrease in human immunity, making it susceptible to various infections. People with HIV/AIDS (PLWHA) face various symptoms related to HIV for a long time and must struggle to overcome various physical, social, poverty, depression, and cultural beliefs that can affect quality of life. This study focuses on exploring the fulfillment of basic needs based on the concept of *peaceful end of life* in AIDS patients which include, free from pain, get comfort, get dignity and respect, be at peace and experience closeness to significant others and those who care. The design of this study is qualitative with a narrative study approach. Using *purposive sampling technique* with a sample of some PLWHA in the Peer Support Group (KDS) of Kediri City totaling 4 informants. Data collection was carried out by in-depth interview with semi-structured interviews, the results were analyzed using an inductive thinking process. The results of the study showed 4 concepts of the *Peaceful End of Life theory*, namely free from pain, get comfort, get dignity and respect, closeness to significant others and those who care have been fulfilled, 1 concept that has not been fulfilled is being at peace. Peace is a need for every individual, both healthy and sick, especially for people with terminal illnesses such as AIDS. In people with HIV and AIDS (ODHA) in the Peer Support Group (KDS) in Kediri City, this has not been met. This is because because of feelings of fear of death, concerns about their health condition and anxiety about changes in their status in society or in their work environment.

**Keywords: AIDS, Peaceful End of Life**



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## INTRODUCTION

HIV and AIDS are global health problems that exist in almost all countries, including Indonesia. The growing problem related to HIV and AIDS is the increasing incidence rate with a high mortality rate (Nasrudin, 2007). HIV ( *Human Immunodeficiency Virus* ) is a virus that attacks the human immune system and weakens the body's ability to fight all diseases that come (Murni, 2011). Uncontrolled HIV will cause AIDS or *Acquired Immune Deficiency Syndrome* . AIDS is a collection of symptoms of disease that arise due to a decrease in the immune system due to HIV infection. The decreased immunity of people with HIV / AIDS (PLWHA) makes the person very susceptible to various infectious diseases (opportunistic infections) which result in death (Ministry of Health of the Republic of Indonesia, 2014). Opportunistic infections experienced by PLWHA with advanced HIV cause disruption of various aspects of basic needs, including disruption of oxygenation, nutrition, fluids, comfort, coping, skin integrity and socio-spiritual needs. This basic needs disorder manifests itself as chronic diarrhea, chronic pain in several parts of the body, weight loss, weakness, fungal skin infections, and even distress and depression (Tengah DKPJ, 2013).

WHO stated that HIV continues to be a major global public health problem that has killed more than 35 million people so far. It was recorded that 1.0 million people died from HIV worldwide in 2016 and at the end of 2016 there were 36.7 million people with HIV spread throughout the world with 1.8 million new sufferers, 54% of whom were adults and 43% of children living with HIV are currently receiving lifelong antiretroviral therapy (ART) (WHO, 2017). In Indonesia from 2005-2015 HIV cases have increased, in the last 10 years there have been 184,929 reported cases of HIV/AIDS. The highest number of HIV cases is DKI Jakarta (38,464 cases), followed by Papua (20,147 cases), West Java (17,075 cases), and Central Java (12,267 cases), while East Java ranks 2nd out of 34 provinces in Indonesia with 24,104 cases (Minister of Health Decree, 2016). It was recorded that from 1989 to September 2016 there were 54,275 PLWHA, of which 36.88 people had HIV, while the number of PLWHA was 17,394 people. Of the 17,394 people recorded over the past 27 years, 3,679 people died (Jaleli, 2016) . Meanwhile, in Kediri City itself, there were 200 sufferers, with 133 men and 67 women. Based on these data, the most dominant adult age group is 20-24 years old with 30 people, 25-29 years old with 42 people, 35-39 years old with 28 people, from these data it was found that 18 people died due to HIV/AIDS and 182 were still alive (Kediri City Health Office, 2017).

The results of a preliminary study conducted by researchers in February 2018 by interviewing the head of the Peer Support Group and several of its members, obtained data that most of the KDS members had experienced opportunistic infections. Of the various opportunistic infections, pulmonary TB, *candidiasis*, *herpes*, *human papilloma virus/condyloma*, *cryptosporidiosis*/diarrhea, *histoplasmosis*, *Westing syndrome* are the most common infections suffered by HIV/AIDS sufferers in the Peer Support Group of Kediri City, from these infections causing symptoms such as pain in several parts of the body, weakness, stress, discomfort, weight loss, and coughing for a long time (KDS, 2018) .

*Acquired Immune Deficiency Syndrome* (AIDS) is a collection of symptoms of diseases caused by the *Human Immuno Deficiency Virus* (HIV). The HIV virus damages the human immune system, causing sufferers to lose their immune system, making them easily infected and die from various infectious diseases (opportunistic infections). Until now, no preventive

vaccine or drug has been found that can completely cure this disease. The time between infection and the appearance of symptoms of the disease in adults takes an average of 5-7 years. During this period, even though they still look healthy, people with HIV can consciously or unconsciously transmit the virus to others (Aleka, 2016).

*The Peaceful End Of Life* theory was developed from standards with the aim of being able to live peacefully before life ends. According to one of the nursing theorists Shirley M. Moore, the *Peaceful End Of Life theory* states that nurses integral to the end of life peace include, freedom from pain, emotional support, closeness and participation in other influential realities, and treatment with empathy and respect (Alligood, 2014). This theory does not only focus on the death of the patient, but the peace and meaning of life during the end of life that can be remembered by the patient, other realities and family members. The theory was developed from a standard of concern created by nursing experts to manage patients with terminal illnesses (Ruland and Moore 1998).

### **Research purposes**

This study aims to explore the fulfillment of basic needs based on the concept of *peaceful end of life* in AIDS sufferers, which includes : freedom from pain , gaining comfort , gaining dignity and respect , being at peace and experiencing closeness to significant others and those who care .

## **MATERIALS AND METHODS**

The design of this study is qualitative with a narrative study approach. Using a *purposive sampling technique* with a sample of some PLWHA in the Peer Support Group (KDS) of Kediri City totaling 4 informants. Data collection was carried out by *in-depth interviews* with semi-structured interviews, the results were analyzed using an inductive thinking process.

## **RESULT**

### **Subject Characteristics**

**Table 1.** Characteristics of respondents in this study are:

1. Informant 1 is a 38-year-old housewife, diagnosed with HIV/AIDS approximately 10 years ago. She explained that the HIV infection was obtained from her husband who works as a migrant worker. She explained that she has been taking ARVs for approximately 10 years.
2. Informant 2 is a 28-year-old man, diagnosed with HIV/AIDS approximately 5 years ago. He explained that the HIV infection was obtained from a prostitute (WTS) when he used to work in Surabaya. He explained that he had been taking ARVs for approximately 5 years.
3. The third informant is a 47-year-old housewife who was diagnosed with HIV/AIDS approximately 18 years ago. She explained that she got the HIV infection from her husband who works out of town. She explained that she has been taking ARVs for approximately 18 years.
4. The fourth informant is a 42-year-old man who was diagnosed with HIV approximately 12 years ago. He explained that his HIV infection was acquired from his past use of injecting drugs. He explained that he had been taking ARVs for approximately 12 years.

## DISCUSSION

### Free from Physical Disturbances

The results of the study conducted by interviewing 4 informants of PLWHA in the Peer Support Group (KDS) of Kediri City showed that physical disorders experienced by PLWHA are symptoms that arise due to opportunistic infections. Opportunistic infections that often occur in PLWHA in the Peer Support Group (KDS) of Kediri City are *oropharyngeal candidiasis*, digestive tract infections, and *generalized dermatitis*. These opportunistic infections then cause symptoms such as fever, diarrhea, mouth ulcers, chronic pain, *Westing syndrome*, and itching of the skin. The findings of this researcher are reinforced by the theory put forward by the Indonesian Ministry of Health, (2014) AIDS is a collection of symptoms of diseases that arise due to a decrease in the immune system due to HIV infection. The decrease in the immunity of people with HIV/AIDS (PLWHA) makes the person very susceptible to various infectious diseases (opportunistic infections) which result in death.

Opportunistic infections experienced by PLWHA with advanced HIV cause disruption of various aspects of basic needs, including disruption of oxygenation, nutrition, fluids, comfort, coping, skin integrity and socio-spiritual needs. These basic needs disorders manifest as chronic diarrhea, chronic pain in several limbs, weight loss, weakness, and fungal skin infections. However, researchers also found that when PLWHA informants took ARVs regularly according to the instructions given by health workers, it could make PLWHA rarely get opportunistic infections, so that PLWHA can have a better and more productive quality of life. This is also reinforced by the theory put forward by WHO, (2015) that there is no drug or therapy to cure HIV until now, but HIV can be controlled by taking ARVs regularly.

The way ARV works is to suppress and disrupt the process of virus replication in the body, and CD4 in the body will increase, then the process of AIDS can be slowed down and the number of cases of illness and death due to AIDS can be reduced. and also the theory put forward by Mandal, (2008). and also the theory put forward by Silva, et al., (2014) ART compliance is a positive factor in the quality of life of an HIV/AIDS patient, especially in the field of physical health because ART compliance improves immunity, controls viral load and delays disease progression. High ART compliance is associated with the quality of life of patients in the field of physical health because of its contribution to the rapid increase in CD4 counts (Wang, et al., 2009). Low ART compliance is associated with the quality of life of patients in the field of physical health because of the increased intake of antiretroviral drugs. Sarna, et al., (2008). then also supported by the results of Wang, et al.'s research. (2009) who found that ART compliance had a significant relationship with ART compliance in the field of

physical health ( $p = 0.016$ ) and his statement that high ART compliance was also related to the quality of life of patients in the physical field because of its contribution to the rapid increase in CD4 counts (Wang, et al., 2009). HIV sufferers can survive longer if they consume ARVs, because ARVs can suppress the development of the HIV virus. If HIV sufferers are compliant in consuming ARVs, then the survival time is likely to be the same as healthy people without HIV.

Opportunistic infections are the cause of physical disorders experienced by PLWHA, in general physical disorders in PLWHA patients are chronic. ARVs are drugs that can suppress the development and replication process of the HIV virus in the body of PLWHA, so that if taken regularly according to the instructions given by health workers ARVs can minimize the recurrence of opportunistic infections, so that it will also significantly minimize the occurrence of physical disorders in PLWHA and as the final result that can be obtained from compliance with taking ARVs regularly is the possibility of being free from physical disorders is greater.

### **Getting Comfort**

Disturbance of Comfort in PLWHA in Peer Support Group (KDS) of Kediri City is caused by the emergence of opportunistic infections, side effects of ARV which then appear such as nausea. This is reinforced by the theory put forward by Nurpudji Astuti & Sitti Fatimah, (2007) nausea and vomiting in people with HIV/AIDS (PLWHA), can be caused by side effects of drugs taken, excessive anxiety, stress or can be an early symptom of various more serious diseases such as infections in the digestive tract. Comfort in the *peaceful end of life theory* is defined as being free from discomfort, a state of ease, satisfaction and peace, and anything that makes life easy or enjoyable (Rulan & Moore 1998). The desired outcome criteria are: (i) the patient does not feel nauseous, (ii) the patient does not feel thirsty, (iii) the patient feels optimal comfort, and (iv) the closest person who is meaningful to the client feels a pleasant environment.

One of the impacts of the emergence of symptoms of opportunistic infections is the emergence of discomfort disorders in PLWHA, this may last for a long time but again depends on the condition of each individual PLWHA if PLWHA are able to regulate their thought patterns, activity patterns and nutritional patterns then it is possible that they can recover quickly and gradually the symptoms of opportunistic infections will disappear and the need for comfort will also be met.

### **Dignified and Respected**

The findings of researchers who conducted interviews with 4 informants of PLWHA in the Peer Support Group (KDS) of Kediri City found that PLWHA received good service from officers, there was no distinction or discrimination in service between PLWHA and other patients, they were also respected and appreciated like other patients. However, this study also found that the four informants admitted that they were not ready if one day the community knew that they were PLWHA, this was because PLWHA considered that there was still a strong negative stigma that developed in the community towards HIV and AIDS, the four informants stated that they preferred to hide their status as PLWHA because they were afraid that if there were people who knew it would cause a negative response towards PLWHA and also their families.

*peaceful end of life* theory states that every patient with a terminal illness wants to be respected and valued as a human being. The basis of this concept is the idea of personal values expressed by the principle of autonomy or respect for a person. This includes those that are recognized and respected together and do not violate the patient's integrity values (Rulan & Moore 1998). The criteria for the desired outcomes are; (i) Patients and families participate in decision-making regarding patient care, and (ii) Patients and families are cared for with dignity and respect as human beings.

Being dignified and respected is basically the need of every human being regardless of whether they are PLWHA or not, but in fulfilling it, PLWHA are influenced by many factors, one of which is the negative stigma on HIV sufferers which causes them to be ostracized because society considers HIV to be a very dangerous cursed disease and there is no cure, so many HIV and AIDS sufferers choose to live by hiding their status as PLWHA. However, as health workers who certainly have sufficient knowledge about HIV and AIDS, they must serve HIV and AIDS patients well, just like caring for other patients, they must also protect themselves from HIV transmission factors.

## **In Peace**

The results of interviews conducted by researchers with 4 informants of PLWHA in the Peer Support Group (KDS) of Kediri City showed that when they were first diagnosed with HIV, they received counseling from health workers who treated them including the causes, symptoms, transmission methods, treatment and possible complications that can occur due to HIV infection. However, from the research conducted, it was also found that the four informants of PLWHA in the Peer Support Group (KDS) of Kediri City still harbored feelings

of worry, fear and anxiety because they were thinking about their health in the future and also thinking about their families.

The definition of feeling peaceful in the *peaceful end of life theory* involves calm, harmony, and contentment (Rulan & Moore 1998). to be free from anxiety, fear, and worry. The outcome criteria to be achieved are: (i) the patient and family maintain hope and meaning, (ii) the patient and family receive help in explaining the practical and economic issues related to prognosis and an end of life, (iii) the patient does not die alone, and (iv) the patient is at peace.

Peace is a need for every individual, both healthy and sick, especially people who suffer from terminal illnesses such as AIDS, but in fulfilling it, many factors influence it, starting from the nature and characteristics of the individual, then of course the illness they experience, in people with HIV and AIDS (PLWHA) this is often not fulfilled, there are also many causes, starting from the fear of death, concerns about their health conditions and also anxiety about changes in their status, both in the community and in their work environment.

### **Closeness to Family and Caregivers**

The findings of researchers who conducted interviews with 4 informants of PLWHA in the Peer Support Group (KDS) of Kediri City found that in general when informants of PLWHA were sick they were well cared for by their families. The role of the family in caring for PLWHA is very large, their families provide support, encouragement and also help meet their needs when they are sick apart from their families. Researchers also found that when informants of PLWHA were sick and had to contact health services, informants of PLWHA also received good service from health workers who treated them, there was no discrimination from health services in handling patients, both PLWHA and other patients were served equally.

Closeness to family and significant others for the *peaceful end of life theory* is a feeling of connectedness with others who care (Rulan & Moore 1998). The outcome criteria to be achieved are: (i) Participating in caring for patients as they wish, (ii) Being able to say goodbye to patients according to their beliefs, cultural rituals, and wishes, and (iii) Getting information about funeral procedures that may be different. From the description of the interview results above, it can be concluded that the need for closeness to family and caregivers in the four PLWHA informants in the Peer Support Group (KDS) in Kediri City has been met.

Family is the closest person to the patient who has a big influence on the patient's recovery. Support from the family will certainly greatly help the recovery of a patient, especially patients with terminal illnesses such as AIDS, in addition to being supported by

health workers who provide good care to PLWHA patients so that PLWHA patients can feel that they are not alone and there are still people who care about them, this will certainly significantly affect the recovery process in PLWHA patients.

## CONCLUSION

1. Based on the results of the study, it is known that the need to be free from physical disorders in 4 informants of PLWHA in the Peer Support Group (KDS) of Kediri City has been met. The four informants explained that they did not experience opportunistic infections after they routinely consumed ARVs regularly according to the rules conveyed by health workers. The cause of physical disorders is the emergence of HIV concomitant infections or opportunistic infections, from various opportunistic infections that may arise, canker sores, diarrhea, *Westing syndrome*, and skin infections are opportunistic infections that often appear in AIDS sufferers in the Peer Support Group (KDS) of Kediri City before consuming ARVs. From these opportunistic infections, symptoms such as pain, impaired activity, disturbed sleep patterns, disturbed eating patterns, and disturbed feelings of comfort are caused. When physical disorders arise, what PLWHA generally do is seek treatment/contact health services to get treatment and if symptoms appear but it is not time to take medicine they divert it with things they like such as watching television, listening to music and playing games.

2. The need for comfort in PLWHA in the Peer Support Group (KDS) of Kediri City has been met. The cause of discomfort experienced by PLWHA in the Peer Support Group (KDS) of Kediri City is the emergence of opportunistic infections which then cause symptoms such as nausea, but the symptoms of nausea occur only when opportunistic infections are ongoing and/or the PLWHA's body is adapting to ARVs, when that stage is over, nausea no longer appears, and the four informants have gone through that stage so that they no longer experience discomfort. When informants are sick and have to contact health services, they state that they feel comfortable with the situation in the health service related to temperature, smell, lighting, color, and sound.

3. Based on the research results, the four informants of PLWHA in the Peer Support Group (KDS) of Kediri City have received fulfillment of their dignity and respect needs from their families. The four informant families can accept the presence of informants in the family, but the four informants of PLWHA in the Peer Support Group (KDS) of Kediri City have not received fulfillment of their dignity and respect needs from their environment. This is due to the high negative stigma from the community about HIV and AIDS, so the informants are worried that if the community knows their status, they will receive negative



treatment from the community. The four informants of PLWHA in the Peer Support Group (KDS) of Kediri City chose to hide their status as PLWHA from the community.

4. In general, when the first informants of PLWHA in the Peer Support Group (KDS) of Kediri City found out that they were infected with HIV, they felt shocked, stressed and also worried. However, as the knowledge gained increased, the majority of informants felt calmer. The increasing knowledge about HIV and AIDS also had an effect on their self-acceptance as PLWHA, of course with the support of their families and the Peer Support Group (KDS) of Kediri City. However, researchers also found that in general, every PLWHA who was an informant in this study still had feelings of anxiety and worry related to their health conditions in the future.

5. The results of the study showed that the need to experience closeness with the closest people in this case is their family and service providers in the four informants has been fulfilled. The results of the study showed that when informants were sick they were treated well and also given support to recover quickly by their families. When informants contacted health services they explained that they received good service from the health workers who treated them, there was no discrimination from service providers between PLHIV patients and other patients.

## REFERENCE

- Aleka Zulfikar, (2016). "HIV/AIDS Control Strategy". (<http://dinkes.bengkuluprov.go.id>). Accessed: 15 Dec 2016.
- Arikunto, Suharsimi. (2010). *Practical Approach Research Procedures* . Jakarta: Rhineka Cipta.
- Central DKPJ. (2012). Health profile book of Central Java province 2012.
- East Java Health Office, (2014). *HIV and AIDS cases in East Java* . East Java Health Office
- Hidayat, A. Aziz Alimul. (2008). *Nursing Research Methods and Data Analysis Techniques* . Jakarta: Salemba Medika.
- Jaleli. 2016. "HIV-AIDS Sufferers in East Java are the Highest, but Mortality Rate is Low". (<https://m.detik.com> news). accessed on February 7, 2018.
- KPA. 2007. *National Strategy for Combating HIV and AIDS 2007-2010*. Final Draft 0401007. Jakarta. Ministry of Health.
- Ministry of Health of the Republic of Indonesia. (2014). Situation and analysis of HIV AIDS. Jakarta: Data and information center of the Ministry of Health of the Republic of Indonesia.
- Ministry of Health of the Republic of Indonesia. (2016). " *HIV-AIDS & Sexually Transmitted Infections (STI) Case Development Report Surabaya* : Airlangga University Press.

- Ministry of Health, Republic of Indonesia (2009). *National guidelines for care, support and treatment for odha*. A guidebook for health workers and other officers. Jakarta: Directorate General of PPM and PL, Ministry of Health.
- Ministry of Health. (2016). Information Center for Data and Information. Ministry of Health of the Republic of Indonesia.
- Murni, Suzana, et al. (2009 ). *Living with HIV/AIDS* . Jakarta: Spiritia Foundation.
- Notoadmojo, S. 2010 . *Health Research Methodology* . Jakarta: PT. Rineka Cipta .
- Nugroho, Setyo A. (2014). *Middle Range Theory: Peaceful End Of Life Theory*. Academia.edu. Downloaded on February 7, 2018.
- Nursalam . ( 2007 ) . *Nursing Care for Patients Infected with HIV/AIDS*. Jakarta: Salemba Medika .
- Nursalam and Ninuk. ( 2013 ) . *Nursing Care for Patients Infected with HIV/AIDS*. Jakarta : Salemba Medika .
- Nursalam. (2008). *Concept and Application of Nursing Science Research Methodology, A Guide to Thesis, Dissertation and Research Instrumental*. Jakarta : Salmba Medis.
- Sarafino E. P. (2011). *Health psychology: biopsychosocial interactions* (7th ed). Canada: John Wiley & Sons, Inc.
- Sarafino, E. P. ( 2006 ) . *Health Psychology: Biopsychosocial Interactions. Fifth Edition*. USA : John Wiley & Sons.
- Spiritia Foundation. (2008 ) . *Information Sheet on HIV and AIDS for People Living with HIV and AIDS (ODHA)* . Jakarta: Spiritia Foundation .
- Sugiyono. 2011 . *Qualitative Quantitative Research Methods and R&D* . Bandung: Alfabeta .
- Tomey, A. M., & Alligood, M. R. (2010). *Nursing Theorists and Their Work*, ( 6th ed ). St. Louis, Missouri : Mosby Elsevier.
- Tomey, A. M., & Alligood, M. R. (2014). *Nursing Theorists and Their Work, Sixth Edition*, St. Louis Mosby.
- WHO. (2016). “Global Report 2016”. (<http://www.who.int>). Retrieved on 18 February 2017.