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## **EXPERIENCE OF ELEMENTARY SCHOOL-AGE CHILDREN LIVING WITH HIV AIDS AT PUSKESMAS SENTANI IN JAYAPURA PAPUA STUDY PHENOMENOLOGY DESCRIPTIF**

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### **ABSTRACT**

*The phenomenon that occurred in HIV-positive children, which is that it takes weeks to months to receive their own disease. HIV-positive children experience indirect occurrences of stigma and discrimination. HIV-positive children view drug consumption as a necessary ordeal to keep them healthy. The impact on children with HIV/AIDS varies greatly, namely the social, economic, and psychological impacts are profound. This study aims to explore the experiences of school-age children living with HIV/AIDS at the Sentani Health Center in Jayapura District, Papua. The design of this research uses phenomenological approach. Data retrieval techniques with purposive sampling and snowball nature. Participants in this study were children living with HIV AIDS, totaling six people. Data collection by means of semi-structured indepth interviews. The analysis uses thematic according to Colaizzi's methode.*

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## A. BACKGROUND

The researcher's experience while returning to serve as a nurse who treated patients with Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) at Walihole Yoka Jayapura Papua Clinic in early 2020. Researchers looked at the lives of school-age children with HIV AIDS in growing and growing up not according to age, children were discriminated against in families, neighborhoods, and schools, children neglected with ARV therapy so that they were delivered by family or closest people to be treated at the clinic.

Researchers looked at school-age children with HIV AIDS in poorly maintained conditions. School-age children with HIV AIDS are very happy when they are in the clinic, many friends or people with HIV AIDS who encourage school-age children with HIV AIDS to stay motivated, and should be able to go back to school when they return home.

Based on the results of the interview researchers in Puskesmas Sentani Jayapura District. On January 31, 2020, interview with nurse R, who handles patients with HIV / AIDS as follows: *"Puskesmas Sentani has 6 school-age children patients, namely 7 - 12 years old. Three men, three women who live with their families, some who live with parents (bapa, mama) there are those who live with families such as (nene, tete, tanta, om, mama ade, bapa ade) because their parents has died from HIV AIDS infection. The six children are still active in Antiretroviral (ARV) treatment until now.*

HIV/AIDS cases in Puskemas Sentani city in 2019 obtained through voluntary test counseling approach (KTS) as many as 299 people were

declared reactive, through counseling initiative health officers (KIPK) as many as 1,514 people declared reactive. Of the numbers listed above, there are 6 children living with HIV /AIDS. The six children are still active in ARV treatment until now (Secondary Data of Puskesmas Sentani, 2019).

HIV/AIDS cases in Jayapura district as of December 2016 amounted to 2,281 cases (HIV 1,246 and AIDS 1,035 cases). People with HIV/AIDS died in 242 cases. HIV/AIDS attacked the productive age of 2,115 cases: ages 15-19 years 206 cases, age 20-29 years 1,117 cases, age 30-39 years 598 cases, age 40-49 years 194 cases (Secondary Data Health Department of Jayapura District, 2017).

According to the report of the Directorate General of Disease Prevention and Control in 2017 quarter 1, the number of HIV cases in the Papua Province as many as 25,586 cases, increased when compared to the number of cases in 2016 quarter 1, namely 21,747 cases. In December 2016, a report by the Papua Provincial Health Office showed 4162 cases of HIV in Nabire District, 6107 cases of Jayapura City, and 5293 cases of Jayawijaya Regency. This is in line with research conducted by Pariaribo et al., (2017) that Papua Province in 2014 has the highest prevalence of all provinces in Indonesia which is 359.42/100.000 inhabitants (Health Department of Papua Province, 2019).

The number of AIDS Infections in Indonesia reported by the Province as of December 2018 in the 10 largest rankings are as follows: Papua and West Papua (21,470 people); East Java (18,243 people); JAKARTA (9,215 people); Central Java (8,170 people); Bali (7,441 people); West Java

(6,502); North Sumatra (3,916 people); South Sulawesi (3,079 people); and Banten (2,782 people); and West Kalimantan (2,600 people). The statistics above show that Papua ranks first in the highest number of AIDS nationally. And Sentani is one of the districts of Jayapura as the capital of Papua. Number of AIDS infections reported in 2017 in children under the age of 1 year (102 people); age 1 - 4 years (154 people), age 5 - 14 years (106 people), and 15 - 19 years (195 people) (Ministry of Health RI, 2018).

*The 30<sup>th</sup> World AIDS Day* on December 1, 2018, statistics of living sufferers with HIV globally in 2017 were 36.9 million with the following description: 35.1 million in adults and 1.8 million in children under the age of 15 years. Living sufferers total with HIV/AIDS globally: East and South Africa (19.6 million); Central and Western Africa (6.1 million); Asia Pacific (5.2 million); Western and Central Europe and Eastern America (2.2 million); Latin America (1.8 million); Eastern Europe and Central Asia (1.4 million); Caribbean (310,000); Middle East and North Africa (220,000). Asia Pacific ranks third in living sufferers total with HIV/AIDS, one of the Asia Pacific states is Southeast Asia and Indonesia is part of Southeast Asia (Joint United Nations Programme on HIV/AIDS (UNAIDS), 2018).

HIV/AIDS infection was first reported in the Americas in 1981 in adults with homosexuality (World Health Organization (WHO), 2017). Meanwhile, the first HIV/AIDS case in Indonesia was found in Bali in 1987. The first case of HIV/AIDS in Papua was discovered in Merauke in October 1992 from a Thai fisherman. Spreading throughout Papua, even in remote districts,

HIV/AIDS cases were also found (Nasronudin, 2014). HIV/AIDS is now widespread throughout the world. Transmission continues, 16,000 new infected people every day (Nasronudin, 2014).

In December 2002, 3.2 million children under 15 were living with HIV/AIDS, a new infection that occurred in 800,000 children in 2002. Most infected babies/children come from HIV-infected mothers, transmission during the perinatal period occurs in the intrauteri (transplacental), intrapartum, post partum (especially through breast milk). Research submitted by Ernawati, Suryoputro & Mustofa (2016) explained that transmission of HIV infection from mother to child is the main cause of HIV infection in children under the age of 15 years. Approximately 85-90% of HIV infections in children are obtained in childbirth from HIV-infected mothers, while partly due to blood transfusions or HIV-contaminated blood components. Transmission via breast milk 14% occurs in the first 6 months of post partum.

The period of school-age children is often referred to as middle age or latent period, the time to have new challenges. The cognitive power to think of many factors simultaneously gives school-age children the ability to evaluate themselves and feel the evaluation of their peers (Potter et al., 2016). At this time their understanding of knowledge and concepts of healthy, sick, treatment can be taught, but usually they do not understand very well the treatment done to the disease. This is not an easy challenge for school-age children in line with research conducted by Triana Ayu Hapsari & Muhammad Azi (2018). HIV-positive children take weeks to months to receive their own disease. HIV-positive children are reported to experience

indirect instances of stigma and discrimination. HIV-positive children view drug consumption as a necessary ordeal to keep them healthy.

Nurses as an integral part of the health care team are instrumental in realizing a quality life for patients, especially in children with HIV/AIDS in providing comprehensive and holistic nursing care that includes bio, psycho, socio, and spiritual (Potter et al., 2016). This means that in seeking the degree of child health, nurses not only focus on the use of physical problems but also play a role in preventing and addressing the problems of growth and development of children in the stages of growth and development.

Based on this, it is considered necessary to descriptively explore qualitative phenomenology to explore the phenomenon that occurs in the experiences of school-age children living with HIV/AIDS by describing facts related to information obtained from informants about the experiences of school-age children living with HIV AIDS through in-depth interviews. In-depth interviews were conducted because researchers wanted to gain an experience from each individual (a different point of view from each participant) about the experiences of school-age children living with HIV AIDS.

Researchers are hoping for something new about the experiences of elementary school-age children living with HIV AIDS. this information can be used as a basis in providing nursing services for elementary school-age children living with HIV AIDS. Therefore researchers are interested in conducting research on the experiences of elementary school-age children living with HIV AIDS.

## **B. RESEAR OBJECTIVES**

The purpose of this research is to explore the experiences of elementary school-age children living with HIV AIDS at the Sentani Health Center in Jayapura District.

## **C. THEORETICAL REVIEW**

One of the chronic diseases in children is HIV. HIV is a Human Immunodeficiency Virus that causes AIDS. Most children under the age of ten who are infected with HIV are infected from their mother. Transmission can occur in the womb, during childbirth or through breast milk (Directorate General of P2 &PL, 2016). The same was said by (Nasronudin, 2014) that mother-to-child transmission is the main route of HIV infection in children.

School-age children are children aged 6-12 years, at this age the child acquires a basic knowledge and skills for the success of the child's self-adjustment in his adult life. At this time the child is more likely to engage with his peers, in this case children with HIV / AIDS can affect specifically his compliance in treatment that is with the period of growth and development. Children's abilities and needs will change according to the stage of growth both physically and emotionally which is a dynamic challenge over time. The challenge found in school children is often developing a capacity for understanding the healthy concepts of illness and care, but usually they are not aware of the disease. ( Yusuf, 2019).

## **D. METHODOLOGY**

The research design used is qualitative design with descriptive Phenomenological approach (Creswell, 2014). The descriptive use in this study was to explore data and information on new topics or

issues regarding the experience of elementary school-age children living with HIV AIDS at Puskesmas Sentani, about their life experiences with HIV AIDS through research directly conducted by researchers to participants. Researchers empower children with HIV AIDS to be able to tell their stories and to hear their voices firsthand.

Participants in this study were elementary school-age children who are still active in Antiretroviral (ARV) treatment at Puskesmas Sentani until now.

Inclusion criteria as follows research.

1. School-age children living with HIV AIDS approximately 6 months
2. Children are cooperative in following interviews
3. The child is willing to be a participant and willing to share his experiences

Sampling techniques: Data collection techniques *purposive sampling* and nature. *snowball sampling*. *Semi-structured in-depth* interview Analysis using thematic according to Collaizz's methode (Creswell,2014). The instrument of this study is the researcher himself. Researchers used a voice recorder such as a Samsung A20 mobile phone, other tools paper and pen.

The process of data analysis conducted by researchers is through the following stages:

1. Researchers conduct a process of documentation of data collection results immediately after the data retrieval process.
2. Researchers read transkrip and interview notes in the field repeatedly
3. Create categories of questions.
4. Determine the categories of questions into meaningful and related questions and then make some sub themes and themes.

5. Classify similar themes then compared with the result description in transcript.

6. Write a perfect description, clarify the data that is not clear and get additional data.

7. Bring together new information or new data into the theme group of the participants' clarifications by adding and improving the perfect description

8. Create a final description in narrative form to present.

## **E. RESEARCH RESULTS**

Participants in this study there were 3 participants directly involved, with the age of participants between 6 - 12 years, all participants educated elementary school (Elementary School), participants one grade 6 elementary school, participants two fourth grade elementary school, participants three grade 1 elementary school. 1 Christian participant, 2 Muslim participants, one participant from Biak (Papua) and two participants came from Fak-Fak (Papua) tribe. The characteristics of the participants are as follows:

1. Participant 1: a girl, aged 12 years with HIV positive has undergone ARV therapy for 12 years and 2 months. Her parents has died, she lives with his grandmother, and calls her grandmother *mama*. Initial start of ARV therapy on November 12, 2008.
2. Participant 2: a 10-year-old girl, living with her mother, her father has died, she has undergone ARV therapy for 6 years and 7 months. Initial start of ARV therapy on July 13, 2013.
3. Participant 3: a boy with HIV positive aged 6 years, living with his mother, his father has died, he has undergone ARV therapy for 6 years 5. Initial start of ARV therapy on January 3, 2015.

The results of the study obtained 6 themes. The theme is as follows: The results of the thematic analysis with 3 participants obtained 6 themes, namely: 1. Barriers that occur in children with HIV AIDS [2.Lack](#) of knowledge in school-age children about HIV AIDS 3 disease. Feel afraid to play with friends 4. care of children with HIV AIDS in maintaining personal hygiene 5. Feel confident about ARV treatment and feel confident in prayer 6. Support obtained by children with HIV AIDS. The six themes will be explained as follows:

## **F. DISCUSSION**

This study focuses on the experiences of school-age children with HIV/AIDS. Based on the results of the study identified six themes: themes that occur in children with HIV AIDS, Lack of knowledge about HIV AIDS disease in school-age children, Fear of playing with friends, Care of children with HIV AIDS in caring for personal hygiene, Feeling confident in ARV treatment and feeling confident in prayer and prayer, Support obtained by children with HIV AIDS.

### **1. Barriers that occur in children with HIV AIDS**

The findings of this study reveal about the barriers that occur in children with HIV AIDS experienced by children. Bored, among them bored because of the old ARV therapy, bored because every morning and afternoon must prepare medicine (soak in water), bored because every morning and afternoon must do regular oral hygiene every day, if it does not it then there will appear a lot of mushrooms.

Obstacles are circumstances that cause the implementation to be disrupted and not carried out properly. (KBBI, 2020). Obstacles that occur in

children with HIV/AIDS is the awareness of children to take drugs and awareness to do personal hygiene routinely. They tend to be saturated taking drugs even they do not understand and do not know what HIV/AIDS disease is. Thus awareness of taking drugs regularly is low (Siti Nurhayati, 2018). The research conducted by researchers is in line with the research conducted by other researchers in the paragraph above. The lives of children with HIV/AIDS are the hardest times. Having to take medication every day and maintain personal hygiene when feeling healthy, children experience fatigue in ARV treatment and personal hygiene treatment (Triana Ayu Hapsari & Muhammad Azinar, 2018).

According to researchers, children need to reach the stage of development like a healthy child in general. So researchers really expect the child to obey the ARV treatment and continue to do regular personal hygiene treatment. Children who have been infected with HIV will be susceptible the disease if they do not receive appropriate treatment. One way to overcome the obstacles that occur in children living with HIV AIDS is that the child should be able to try to eliminate the negative feelings that exist in the child itself, namely boredom, exhausted and lazy.

### **2. Lack of knowledge about HIV/AIDS in school-age children**

The findings in this study revealed about lack of knowledge about HIV/AIDS disease in school-age children, i.e. do not know what HIV/AIDS disease is experienced by the child itself, so must take medication for a long time even though it is healthy, but must take medication so that the child feels confused by HIV/AIDS disease experienced.

Knowledge is the result of human sensing or the result of knowing a person to an object through the five senses of human, namely through the senses of vision, hearing, smell, taste and feel. Most of human knowledge is obtained through the eyes and ears (Notoatmodjo, 2017). Lack of knowledge is possible due to the age factor of the child which is still very easy. Thus causing a lack of knowledge and understanding about HIV / AIDS. (Marsito & Saraswati, 2016).

According to researchers, knowledge has a great influence on children with HIV/AIDS. When children with HIV/AIDS have a broad knowledge and understanding related to HIV/AIDS, it can provide a positive understanding in children with HIV/AIDS. So that children living with HIV / AIDS have sufficient knowledge about HIV/AIDS disease.

### **3. Feel afraid to play with friends**

The findings in this study revealed the fear of playing with friends. Fear expressed by participants is afraid to play with friends at school, and friends in the neighborhood because they are often bullied and hit, so the child prefers to be alone at school or at home.

Fear is a situation where an individual cannot be calm in overcoming the emotions that are churning on him, which is caused by a bad label or stamp given to the individual. For instance anxiety, nervousness, worry, feeling very afraid, alert, uneasy horror. Children with HIV usually become denial, withdraw, fear of peer rejection, anxiety that results in poor appearance at school, depression, isolation and even tend to be silent (Nurhayati, 2018).

This study explains about the bad label or stamp given by peers to school-age children living with HIV AIDS, namely sick children, so that it is shunned by friends at school and in the neighborhood around the house, the labeling makes children prefer to be alone. Labeling a person or group for characteristics inherent to him or her. These traits can be derived from prominent physical traits, sedentary diseases suffered, a person's character, sexual orientation, collective characteristics of race, ethnicity and class (Kushendar & Apprezo Pardodi Maba, 2017) Research conducted by researchers in line with the above study, explaining about negative labels or bad stamps given by peers to school-age children living with HIV AIDS.

### **4. Care for children with HIV/AIDS in caring for personal hygiene**

The findings of this study reveal about the treatment of children with HIV AIDS in caring for personal hygiene. participants suggested that they were able to take care of personal hygiene. Always take a bath in the morning and afternoon, if the child does not it, will appear scabies on all parts of the body, bathing using soap, toothbrush, tongue brush, if not brushing the tongue will appear white fungus on the mouth, always use shampoo to wash hair every day otherwise using shampoo will appear mushrooms such as dandruff on the head , after bathing change of clothes clean.

Children with HIV/AIDS are susceptible to disease. The lack of knowledge and awareness of children in paying attention to personal hygiene will cause health problems, such as skin diseases will be easier to attack (Kusmiyati, Muhlis & Bachtiar, 2019).

The above statement explains about personal hygiene and the effects of not doing personal hygiene this is in line with research conducted by researchers that children who do personal hygiene bath using soap, toothbrushes, hair wash using shampoo maintained cleanliness so as to avoid skin disease disorders.

#### **5. Feeling confident in ARV treatment (Antiretroviral and feeling confident in prayer)**

The findings in this study revealed that they feel confident in ARV (antiretroviral) treatment and feel confident in prayer. Participants suggested that the belief in ARV treatment should be diligent in taking medication in order to stay healthy can be a successful school and can take care of parents.

The belief of prayer, participants revealed parents (mama) and pastors said that by praying and believing in God can certainly be cured. Prayer is very important because with prayer God will forgive sins and give what we ask including healing.

Spirituality plays an important role in the treatment of HIV/AIDS. Research on the importance of spirituality in chronic diseases including HIV/AIDS has been conducted. This is in line with research conducted by Aziza (2018), namely the results of the study by providing only ARV without *do'a* therapy shows that the average CD4 levels of HIV/AIDS patients before and after being given ARV therapy are the same (no different). Thus it can be stated that ARV therapy alone does not affect CD4 levels of HIV/AIDS patients. *Do'a* therapy for 30 minutes twice a day significantly affects CD4 HIV/AIDS levels in dr.M. Haulussy Ambon Hospital.

In addition, Hawari revealed that in addition to medical therapy, prayer, prayer and dhikr can increase the body's immunity to the HIV / AIDS virus, according to him people who are high their spiritual also alpha waves in his brain, this makes his life calmer. When praying a person becomes calm and increases his confidence. In such conditions his body secretes cortisol, epineprine and norepineprine which are hormones that flow out of the adrenal glands to ward off stress.

The above statement is comparable to the research conducted by researchers Participants in the study expressed concern about feeling confident in the treatment of ARV (antiretroviral) and feeling confident in prayer.

#### **6. Support obtained by children with HIV/AIDS**

The findings in this study revealed that the support obtained by children with HIV/AIDS is a form of support. Participants expressed the form of support received is information, emotional and social. Sources of support obtained from parents (mama), religious stores, health workers.

According to KBBI (Kamus Besar Bahasa Indonesia) support means contribution or assistance provided. The support obtained is sourced from the government and the community, an important role besides the government and the community is the family. The family is the smallest unit in society here defined as father, mother, child, aunt, uncle, nephew, grandfather, grandmother and even adopted child. Children living with HIV/AIDS need to get support in fulfilling children's rights. (Rakhabauw, 2016).

The five basic forms of social support provided and received are: Emotional Support: covering



expressions of empathy, care, attention. This causes the individual to feel comfortable, calm, possessed, and loved at a time when pressing conditions refer to relief in the form of encouragement, personal warmth, love, or emotional relief. (Rakhabauw,2016).

The study conducted by researchers, found three forms of support provided by the family (mama) religious shop, health workers such as informational, emotional, social support.

According to family support researchers, health workers' support, religious store support, NGO support is very important for children with HIV/AIDS. With the support obtained by children from various sources, can increase the knowledge of children with HIV/AIDS. so that children are able so that children who have HIV/AIDS can grow and develop as healthy children. Children or family members infected with HIV/AIDS should be treated as dignified human beings, because the positive reception and treatment of the family will greatly help overcome external and internal pressures. Provide support to the life of ODHA to live a positive and meaningful life. HIV/AIDS service institutions as the vanguard in providing assistance to the community, especially ODHA.

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