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Family Experiences in Treating Children with HIV/AIDS Through ARV Therapy in Jayapura City

Pengalaman Keluarga dalam Mengobati Anak HIV/AIDS melalui Terapi ARV di Kota Jayapura

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A B S T R A C T

HIV / AIDS is a chronic disease, can not be cured completely and the incidence rate is always there in every year, so it can have broad impact on all aspects of life especially physical, psychological, social, and spiritual. Thus can affect the quality of life of patients themselves. HIV/AIDS infected more than 90% of children in 2020, acquired from their mothers. In accordance, special protection from families is crucial. Antiretroviral is the best therapy in PLWHA children's treatment, and family support is needed to succeed. The objective of this study is to explore in detail family experiences in nurturing HIV/AIDS children with ARV therapy in Jayapura City. Methods: This research is qualitative research with a phenomenology approach. The selection of participants was obtained by purposive sampling, and 8 participants were selected to be interviewed using voice recorder and file notes. Data were analyzed using nine stages of Colaizzi. Results: There are five themes, namely: the initial obstacles faced by the family of ODHA children; Family efforts to care for children living with HIV/AIDS; Constraints in child care; Form of health care workers; Fulfilling physical, psychological, and laboratory needs. Conclusion: Participants lacking in knowledge regarding HIV/AIDS. Consequently, it became the major obstacle faced by families of ODHA children, this affecting delayed child's HIV status, but in terms of child care, there is a lot of support for children

HIV/AIDS merupakan penyakit kronis, tidak dapat disembuhkan secara tuntas dan angka kejadiannya selalu ada setiap tahun, sehingga dapat berdampak luas pada semua aspek kehidupan terutama fisik, psikis, sosial, dan spiritual. Sehingga dapat mempengaruhi kualitas hidup pasien itu sendiri. HIV/AIDS menginfeksi lebih dari 90% anak pada tahun 2020, didapat dari ibu mereka. Oleh karena itu, perlindungan khusus dari keluarga menjadi sangat penting. Antiretroviral adalah terapi terbaik dalam pengobatan anak ODHA, dan dukungan keluarga diperlukan untuk keberhasilan pengobatan. Penelitian ini bertujuan untuk mengeksplorasi secara mendalam pengalaman keluarga dalam mengasuh anak HIV/AIDS dengan terapi ARV. Metode: Penelitian ini merupakan penelitian kualitatif dengan pendekatan fenomenologi. Pemilihan partisipan dilakukan secara *purposive sampling*, dan dipilih 8 partisipan untuk

diwawancarai menggunakan *voice recorder* dan *file note*. Data dianalisis menggunakan sembilan tahap Colaizzi. Hasil: Ada lima tema yaitu: kendala awal yang dihadapi keluarga; Upaya keluarga untuk merawat anak yang hidup dengan HIV/AIDS; Kendala dalam perawatan anak; Bentuk pelayanan petugas kesehatan; Memenuhi kebutuhan fisik, psikis, dan laboratorium. Kesimpulan: Pengetahuan peserta tentang HIV/AIDS masih kurang. Akibatnya, menjadi kendala utama yang dihadapi oleh keluarga anak ODHA, hal ini berdampak pada tertundanya status HIV anak, namun dalam hal pengasuhan anak, banyak dukungan untuk anak-anak.

Introduction

HIV/AIDS is a global disease problem. Recorded 34.5 million people were infected with HIV, with 17.8 million women suffering while 2.1 million are children aged less than 15 years. Southeast Asia ranks second as the most HIV sufferers after Africa, with 3.5 million people and 39% of people with HIV are women and girls (World Health Organization, 2017).

As reported by the Ministry of Health Indonesian Republic, from October to December 2017, the HIV cases reached 14,640 people. The highest percentage of HIV infection is the age group of 25-49 years (69.2%), 20-24 years (16.7%), and ≥ 50 years (7.6%).

More than 90% of children in 2017 were infected with HIV from their mothers. The virus was transmitted to the child during pregnancy, during childbirth, and during breastfeeding. To suppress the virus growth, patients must regularly take antiretroviral (ARV) drugs to prolong their lives (Rahakbauw, 2016).

The Papua Provincial Health Office noted that until 1st March 2021, the number of people living with HIV (PLHIV)/AIDS (PLWHA) in the area exceeded 40,805 cases. Each of the figures is divided into 15,935 HIV cases and 24,870 AIDS cases. All cases were acquired from all districts and cities in Papua province (Public health Office Jayapura, 2021).

Here, the function of the family is a control for a child to show his existence and actualize himself in society. Family is always there when someone needs and provides material and non-material attention and support (Rahmaniyar *et al*., 2018).

In Papua, nurturing infected children is mainly done by their biological parents (60%), 40% by their grandparents, uncles/aunts. ARV treatment is the best treatment for PLHIV, and ARVs usage has succeeded in reducing HIV-related deaths from 1.5 million in 2010 to 1.1 million in 2015 (Safarina & Melanie, 2018).

To achieve the goals of HIV treatment. ARV treatment is needed. Treatment success is assessed from three things: clinical success, where there will be clinical changes in patients such as weight gain. An immunological success is shown—treatment has success in changes of CD4 lymphocyte towards improvement count and virological success.

An essential factor that needs to be considered is the patient's compliance or discipline in taking ARV drugs. Discipline within taking this drug can help maintain consistency in the effectiveness of ARVs in the patient's body, so resistance does not occur and slows the development of the virus in the body.

Patient non-adherence in taking ARV drugs can have a negative impact. Research in the United States proves that even with discipline above 95%, only 81% of people achieve an

undetectable viral load. 95% discipline means that patients forget or are late, taking three doses per month on a schedule of 2 times a day (Hapsari & Azinar, 2017).

Based on the results of a preliminary study conducted at Jayapura City Health Office, there were 103 pregnant women with HIV/AIDS in 2019 and 108 in 2020. Data in 2019 showed 39 children, 14 children who started ARVs. In 2020 there were 41 children with HIV/AIDS, eight children who started ARV (Public Health Office Papua, 2021).

From the interview results with families of PLWHA children, it appeared that the main factor of the drop out cases in PLWHA children were children bored of ARV therapy, then the family let the child not do therapy until the child dropped out of ARV therapy. Another reason is that the distance between domicile and health services is quite far; this hinders ARV therapy.

Therefore, it is deemed necessary to explore qualitatively the experiences of families or caregivers regarding caring for HIV/AIDS children receiving ARV therapy; thereby, the primary obstacles in the family are identified to maintain the child's level of drug adherence. Knowing the existing barriers in PLHIV/PLWHA families who receive ARV therapy can be used as a basis for providing midwifery care services.

Method

This study is a phenomenological Approach that tries to reveal a study of family experiences in caring for children with HIV/AIDS while undergoing ARV therapy.

This research is conducted on the ARV Referral Hospital in Jayapura City and the ARV initiation satellite of the Abepura Regional Hospital at Waena Health Center. With the consideration, currently there are still 41 cases of children with HIV/AIDS and undergoing ARV therapy of 8 children aged 6 months - 5 years. This research was conducted from May 1, 2021 to August 16, 2021.

The determination of participants in this study used a purposive sampling technique. The samples selection was carried out with specific considerations. Including family or primary caregiver who cared for PLWHA children aged six months - five years, had cared for children more than six months, was willing to provide the information needed by researchers residing in the Jayapura City area. From the criteria above, 8 participants met the criteria.

The research instrument used was an interview guide, made by the researcher in the form of an interview framework with the central questions including obstacles and challenges in caring for children with HIV/AIDS, family care for children with HIV/AIDS, services provided by health workers, physical and psychological needs. And laboratories in children with HIV/AIDS. In this study, researchers used a voice recorder, namely the OPPO A83 cellphone, interview guides, and field notes.

The data analysis technique used 9 Colaizzi stages. For research trust, four aspects in data validation need to be included, namely: *credibility* (data trust), *transferability* (data transferability), *dependability* (dependence), and *confirmability*.

This research has received an ethical permit from the Health Research Ethics Commission of the Jayapura Ministry of Health Poltekkes number 060/KEPK-J/VI/2021.

Result and Discussion

Table 1. Main Respondent Characteristics

Participant	Sex	Age	Education	Occupation	Relationship with Children
P1	F	31	Middle School	Housewife	Birth Mother
P2	F	39	Middle School	Housewife	Foster Mother
P3	M	29	Primary School	Private Employee	Birth Father
P4	F	60	Primary School	Private Employee	Grandmother
P5	F	17	Secondary School	-	Aunt
P6	F	27	Secondary School	Housewife	Birth Mother
P7	F	19	Secondary School	Housewife	Birth Mother
P8	F	20	Secondary School	Housewife	Birth Mother

Table 2. Characteristics of Supporting Respondent in Families

Participant	Sex	Age	Education	Occupation	Relationship with Children
K1	M	35	Secondary School	Private Employee	Birth Father
K2	M	43	Middle School	Private Employee	Foster Father
K3	F	22	Primary School	Housewife	Birth Mother
K4	F	36	Secondary School	Private Employee	Aunt
K5	F	40	Secondary School	Private Employee	Aunt
K6	F	45	Middle School	Housewife	Grandmother
K7	F	55	Primary School	Housewife	Grandmother
K8	F	50	Middle School	Housewife	Grandmother

Table 3. Characteristics of Health Workers Triangulation Respondents

Participant	Sex	Age	Education	Occupation	Relationship with Children
T1	F	48	Bachelor	Doctor	Health Workers
T2	F	47	Master	Nurse	Health Workers
T3	F	48	Bachelor	Nurse	Health Workers
T4	F	57	Diploma	Midwifery	Health Workers
T5	F	43	Bachelor	Doctor	Health Workers
T6	F	43	Bachelor	Nurse	Health Workers

This study discusses the experiences of parents caring for children with HIV/AIDS undergoing ARV therapy in Jayapura City. From the results of analysis data, researchers were able to identify five main themes and sub-themes, namely:

Fist Theme (1): Initial Obstacles Faced by Families of PLWHA Children

First Su Theme (1.1): Limited Information about HIV/AIDS

Limited information about HIV/AIDS makes the families of PLWHA children not know the status of the disease from an early age. Without knowledge, families cannot make decisions that can save their child's lives. Below is the following participant expressions:

"..That virus is a virus that is sexually transmitted. If the HIV is like we mean, we are weak, we are weak, then our bodies go down like that.." (P1)

"..Yes, HIV is a killer, so that's all I know.."(P2)

"..HIV is a contagious disease, that's all.." (P5)

"..HIV is what I know ee.. germs that are in the blood, yes or a virus that is in the blood that can be infected only through intercourse, it can't be transmitted externally like touching or something, but

it can be through blood contact or contact directly like intercourse or through a syringe, as far as possible hehehe..” (P6)

“..What is HIV..have you heard from people that HIV is a disease, what is this virus that you say is difficult to treat.. there is no cure for this disease yet..HIV..” (P7)

Limited knowledge and understanding in families of PLWHA children are due to the lack of information about HIV/AIDS and related issues. This ignorance has impacted the treatment processes and cares carried out by the families of PLWH (Rahakbauw, 2016).

Perceptions of the patient's family who need knowledge of HIV/AIDS, the signs and symptoms, and the transmission mode may occur because the family has not received specific information about it (Waluyo *et al*., 2014).

Researchers see that understanding the transmission of HIV to infants and children is a complex knowledge and must be taken seriously due to increasing cases from year to year. The accuracy of information disseminated to the public determines public knowledge in the prevention and handling of HIV/AIDS cases; if more people cared about finding out the truth, higher life expectancy.

Second Sub Theme (1.2): Delay in discovering child’s HIV status

Almost all families have checked their children to health facilities, although many of them are late. Only the child's deteriorating condition can force the family to go to the health service for a test. Below is the following participant statements :

“..Ee was he born first, he was born, he was only three days old, he didn't breathe until he got green, then that night I took him to Abe, yes, that night he was only born three days. That's why I immediately started crying and then brought it to Abe; then I got the medicine right away..” (P4)

“..When he was only 2, ee two weeks he had a high fever, kept having convulsions, from there he was taken to the hospital, at first I didn't know what disease it was because it was me, but later after three months he got sick again I just took it to the health services from there, then I found out..” (P5)

“..Lung pain, new lungs were admitted to the hospital Abe, only then did the doctor start checking.. just said he had HIV disease..” (P5)

”..It was the day he had a runny nose, so he told me to come and take him for a check-u,p, and he found out he had lungs. So he had HIV once in his lungs… he was immediately found out he had HIV, so he was told to take medicine regularly.. come check it.. disease.. then you just take medicine regularly..” (P8)

The presence of the HIV virus can be identified through laboratory examination from samples of body fluids such as blood. Usually the VCT examination in children is carried out after one of the parents dies of HIV or the child has contracted a serious illness. Children whose status is still in the HIV phase do not show symptoms, unless they have entered the AIDS phase (Hapsari & Azinar, 2017).

The researcher saw that the limited information about HIV/AIDS made the family not know the status of their child's illness from an early age. Without knowledge, people cannot make decisions that can save their lives.

Second Theme (2): Families Effort in Nursing Children with HIV/AIDS

First Sub Theme (2.1): Responsibility in Giving Children ARV Promptly

Giving ARVs to children according to a schedule is a family responsibility, because judging from the age of children who are still under parental control and adherence to ARV therapy itself is the main thing in HIV/AIDS treatment, the success of treatment can be assessed from the health status and growth of children from increasing age. they. This is in accordance with the following participant statements:

"..The drink must be right and on time, it must not be violated, it must not be at will, say ahh for a moment, so you can't. From the beginning we have set the time from 12 to 7 pm. We have to set the time.." (P1)

"..So every day there are 4 drugs, right, so 2 of them have been crushed, so 2 are directly swallowed, so if it's 9 in the morning, it's 9 in the morning, here, people say that if you take medicine, you have to eat first, right? because he's afraid that it's Cotri, he's wasting water, so we give him food first and then give him a drink.." (P2)

"..I take care of this little boy since he left the hospital, I know he has been infected with HIV disease. I take care of him so he doesn't forget to eat, take medicine because I consider it is my daily job. I use a clock every day. The clock is past 8:10.." (P3)

"..We give medicine to children 2 times a day, in the morning at 7 and at night at 7 after eating. The doctor who told us how to be on time and how to take the medicine.." (K1)

"..Every day he takes the medicine in the morning at 8 and at night at 8. If the husband is at home he usually helps prepare.." (K3)

Children with HIV/AIDS to undergo ARV therapy need to prepare families who accompany children to provide drugs, for this reason, it is necessary to consider both the family, the health team, and other social factors to make a decision to start ARV therapy (Fabanjo & Juanita, 2012).

Compliance with treatment is the client's ability to carry out treatment according to medical instructions. That means the right dose, time and method of administration (Ministry of Health RI, 2017).

It is a family responsibility in giving ARV according to schedule, because judging from the age of children who are undergoing parental control and adherence to ARV therapy: The main thing in HIV/AIDS treatment, the success of treatment can be assessed from the health status and growth of children from increasing their age.

Second Sub Theme (2.2) : Support of family members in Nursing HIV/AIDS Children

Support from family members of participants is to provide support to PLHIV/PLWHA children and the participants themselves, in the form of providing energy assistance to participants thereby they not always burden themselves, paying attention to children affect their enthusiasm about undergoing ARV treatment for life. They also sometimes take control children to take medicine to the health service. This support helps maintain children's ARV therapy compliance. This is in accordance with the following participant expressions:

"..If it's days like this, maybe I just ask on the phone whether the child has given food, taken medicine, went to the hospital for control, that's it...." (K1)

"..Heem.. so if my wife goes, we usually change guard. Because this is the closest child to maitua.." (K2)

"..My husband and I feel it is our responsibility to take good care of our children. Give medicine every day, and meet other needs.." (K3)

"..It's just me with my nephew, and his grandmother. So if one of them is busy, we take turns taking care of him and paying attention to him.."(K4)

".. Two people sometimes when grandma goes to the market, I know that grandma has given her some medicine.." (K5)

Families give special attention to children, prioritize all their needs, care for them with love and patience, and give encouragement to children living with HIV. (Achema & Ncama, 2016), stated that family members helped identify the care needs of children living with HIV/AIDS, thereby reducing their illness and improving their quality of life.

According to (Rahakbauw, 2016), meaningful and positive family support accelerates healing and increases the confidence of PLWHA in looking to the future. In addition, a conducive and comfortable situation for PLWHA in interacting with the environment and being able to carry out activities and participate in various activities.

Family support shows that the main thing in the care stage of children living with HIV, so you have to build or create a family that can support each other, can help each other when dealing with children's health problems so that the child's health status improves.

Third Theme (3) : Constraint in Child Care

First Sub Theme (3.1) : Not Giving Children ARV Promptly

The importance of adherence to taking ARV drugs in children is very important according to the instructions of health workers for the success of HIV treatment. In this study, participants said that they had been late in giving ARVs to children due to busyness at home or work reasons. This is in accordance with the following participant expressions:

"..Been slow to give ARV a few times because when you are busy at home, but when you remember, give it a drink quickly.." (P1)

"..Yes, if I'm late, if I drink it that morning. I'll give it a drink later tonight.." (P2)

"..He never forgot, this kid said "hey grandma give me medicine first" eh.. gosh I forgot one day.." (P4)

"..So when it's late, it's often done, sometimes we're already active, then we just remember.. just woke up, oh my goodness, my son hasn't taken medicine yet, call home.." (P6)

"..Yes.. it's like being too tired or so busy working at home like you sometimes forget to do it.. There's just a grandmother who used to say "I gave you medicine". love, drink.." (P7)

"..So when parents take their children for control, we also have questions about how to give ARVs. And most of them say that they have been late giving time to take medicine.." (T4)

(Nurhayati, 2018) which states that the quality of life of children suffering from HIV/AIDS largely depends on adherence to ARV therapy. According to (Fabanjo & Juanita, 2012), the factors that affect compliance in this child, when viewed from family or caregiver factors, can occur due to forgetfulness or busyness, or activities outside the home and changes in daily routines. This will clearly affect the success in ARV treatment as well as the hope to improve quality and survival.

The challenge in treating HIV in children is about adherence to medication. Children who do not understand well about ARV therapy, it is hoped that the family will play an active role in their

child's ARV compliance. Due to non-adherence to ARVs, the effectiveness of drugs decreases so that the number of viruses will increase and make children sick easily because the immune system decreases.

Second Sub Theme (3.2) : Covering HIV Status From the Outside Environment

The problems that we often face by families with children living with HIV are when and how to talk about their HIV status to their children, extended family and community, so that the family still keeps the child's HIV status secret on the grounds that the child can still carry out his daily activities in the environment where he lives. This is in accordance with the following participant expressions:

"..No, he just never wants to eat at his house that person doesn't, he's always inside the house, so we also take care of him, we never say play outside, don't have to play outside, he does play outside but we take care of him, can't come enter into the person who owns the house, if he has entered the game, we call him, he enters. So we don't have neighbors like this, they just play normally, in fact, they call him, they don't even know what it's like, don't you know he's in good health?.." (P2)

"..No, neighbors only know about heart disease, that's all.." (P5)

"..There's a mother who has a sister who also helps pay attention, sometimes I feel uncomfortable, "duh, why just keep asking questions...". he asked.. when he got home from work, when we were still taking medicine.. "Is he really sick?".. so I had to repeat the trick again...." (P6)

In this case, interpersonal communication has not been fully established because the family of PLWHA children do not provide information about their status except to those closest to them. Hiding their health status is the communication they do in society. The difficulty of being open about the status of PLWHA itself to their social environment is done to protect themselves from bad responses to PLWHA (Dwianita, 2018).

The attitude of families to hide their child's HIV status is also almost the same as a study conducted by (Achema & Ncama, 2016), in which none of the 9 caregivers had disclosed this to their children and 80% of them did not intend to do so by reason of fear of psychological harm to their children. and only 20% intend to tell the truth when asked by a child (Achema & Ncama, 2016).

When communicating, a person makes limits on the basis of his own considerations and thoughts. His communication was done by covering up his health status in order to gain acceptance for him and his family in the surrounding environment in order to avoid stigma and discrimination.

Third Sub Theme (3.3) : Financial Problem

In general, there are not a few families who experience financial difficulties in accessing health services and in seeking treatment when their child is sick and to meet their daily needs. This is in accordance with the following participant expressions:

"..If we usually do not have HIV, and usually use breast milk, there are no obstacles. But if we are HIV children, the obstacle is milk which is half dead.." (P1)

"..Lack of money, right here, it's delivered here, luckily I get medicine from the puskesmas.." (P5)

"..Sometimes it's like there's no taxi money, so... sometimes the child doesn't come to get the medicine, just wait until there is a new taxi money, I can return, if there is no taxi money I can't come.." (P8)

This is in line with research by (Nurhayati, 2018), which states that the difficulty in accessing the services stated by the informants is caused by transportation costs. This shows that although ARV drugs have been provided free of charge by the government, the financial burden for access and other treatments remains large. In general, there are not a few families who experience financial difficulties in accessing health services and in seeking treatment when their child is sick and to meet their daily needs.

Fourth Sub Theme (3.4) : Seeking Care when Child is Sick

In addition, participants will also seek treatment if the child is sick, as expressed by the following participants:

".If he usually gets sick, I'll immediately take him to the hospital here, I'll take care of him here.." (P2)

"..Yes, sometimes panic, panic because if he's hot, he just has a seizure, he immediately panics, so from there he immediately takes him to the hospital.." (P5)

"..So when he is hot or something, I have to quickly take him to the hospital so that there is treatment, because we don't know, right?.." (P6)

"..It's just normal when he's sick.. At this point, the father immediately said, "Take him to the hospital quickly." So it's normal if he has a grandmother, his grandmother used to tell him to "get him to the hospital quickly" because you know he has lung disease, right?.." (P7)

Children who have been infected with HIV will be vulnerable to disease if they do not get appropriate treatment and care (Nurhayati, 2018).

According to (World Health Organization, 2017), one way to overcome the physical changes caused by HIV/AIDS is to increase the coverage of treatment, support and care. Thus, families must have the ability to recognize children's health problems, decide what action to take, care for sick family members, and take advantage of existing health facilities.

Fourth Theme (4) : Forms of Health Service Officer

First Sub Theme (4.1) : Providing Treatment Information

Information is given to the family at the beginning of treatment and every time they make a visit to a health facility, such as statements expressed by participants as follows:

"..Justin had also stopped taking the HIV drug. When you come here, please explain to me so I just continue again.." (P1)

"..What are you doing here, take good care of him, he's not like entering the hospital here, it's kind of difficult for him, isn't it. In fact, please handle him well too,, just let me know this and this with us.." (P2

"..What do they say... routinely take the medicine and then give it to drink regularly, so that he gets well soon.." (P5)

"...Told to take medicine regularly, don't be late, take medicine again from the date you were told to come back.." (P8)

"..That is, if a child patient has tested positive, the family will be given education on how to administer ARV drugs and take care of them on a daily basis.." (T2)

"..That's every month they come for control, we always give knowledge, advice, and always remind the importance of ARV treatment. So hopefully they understand about HIV and take good care of their children.." (T6)

(Jasmiranda, 2017), mentioned that the support obtained from families and health workers in helping to treat HIV/AIDS patients has an important role for the patients themselves. Support from health workers in providing services to families can increase family enthusiasm in caring for their children. It is hoped that the family will not give up in meeting the needs of their children every day.

Second Sub Theme (4.2) : Home Visit

Health workers also make home visits to monitor treatment, this is a form of support for families as stated by the following participants:

"..Sometimes we have time to visit. We've been visited, seen the state of the house, how to eat enough or not,, like that. The term is no loss of attention.." (P6)

"..If we look at the summary of patient care, he should have checked his schedule to take medicine but he didn't come. We'll call him on the phone to remind him. If he doesn't come, we'll also visit his house and bring him some medicine.." (T5)

The form of service carried out by the officer is by visiting the house where the child PLWHA lives with the intention of seeing firsthand the condition of the home environment, digging up family information in the care of their child every day. In addition, participants also felt that there was informational support, namely that doctors and nurses always provided explanations and information to them about the health status of children and how to care for children with HIV/AIDS in ARV treatment.

The role of health workers is very large to ensure that families maintain adherence to therapy for children, according to the Caring model developed by Swanson that as a nurse not only makes people better, but nurses also make patients aware of caring for others, as they can. going through a period of transition from health, illness, recovery, death all of which are in accordance with his personal values (Fabanjo & Juanita, 2012).

Fifth Theme (5) : Fulfil Physical, Psychological, and Laboratory Needs

Sub Tema Pertama (5.1) : Fulfillment of Physical Needs

Children have very unlimited needs and always increase from time to time. Families of PLWHA children, meet the physical needs of children by providing food and drink, playing and resting. This is in accordance with the following participant statements:

"..If you play almost noon at dawn, then he asks for food, he will definitely give you food and then he plays a lot, then he just eats again. Eat at 7 then take medicine. Taking the medicine, he immediately takes a shower, asking for the clothes. If not, he takes care of the clothes, at least he (the aunt) arranges the clothes. If not, he takes it himself..." (P4)

"..Yes, Everything he asked for was given, like asking for snacks, he was given, if he asked for food, he was given too, everything was given what he asked for. he wakes up from 4 in the morning, from there,, there he eats after that he takes his medicine at 7 o'clock.. After that he plays, plays until 12 o'clock.. At 12 p.m I give him sleep. Give him a nap, after that he wakes up sometimes in the afternoon, sometimes until the night he just wakes up.."(P5)

"..He just plays diligently, plays with him, and your brothers and sisters are busy here and there.. then if you finish playing, maybe take a shower and feed him.. tell him to sleep, sleep.. that's it every day.." (P7)

"..Usually give him food and drink.. take medicine.. if he eats he eats regularly.. what he likes when he eats rice like that.. water is also good..plays too..plays normally, freely.. then no, not picky, eat regularly.. take a nap too, come here right away he sleeps.. instead go straight to sleep.. (P8)

Families have an obligation to meet all the basic needs of children living with HIV and try to always give the best for their children. One of the physical needs is the fulfillment of nutrition in children living with HIV, generally not different from those given to other children. (Nurhayati, 2018), said that the family plays a role in improving health status, overcoming HIV/AIDS including drug administration and fulfillment of child nutrition so as to reduce hospitalizations. Adequate nutrition can prevent malnutrition, inhibit the development of viruses, support the effectiveness of care and treatment and increase the body's resistance to opportunistic infections, so that daily physical activities are not disrupted.

Children with HIV really need adequate nutritional intake to meet the needs in their bodies, parents here play an important role in the nutritional needs of their children who are still in the process of growing and developing (Munir & Romadoni, 2019).

Second Sub Theme (5.2) : Fulfilling the Psychological Needs of Children

In addition, participants also revealed that in meeting the psychological needs of children, families try to be able to create a safe and comfortable situation for their children. Families also try to create a relationship or emotional bond with their child by always giving love. The affection given by the child's family creates various feelings that can support his life with other people. This is as expressed by the following participants:

"..So let's give him what kind of love is this,, we take him, but it's like we're our own child, he can't be separated, let us go to where he is, he'll come with us until we get home,, we're like that too, tong can't give him anything to stay to people,, people, Tong loves him like we love him, doesn't he, so this is so that we want us to be angry with him, this son of mine wants to be angry no matter what, he can't, he says we are playing games, so it's like we want to say he is like this, he can't. I love him the most, he just got closer, it was me.." (P2)

"..It's enough if I give security, if it's security for him, I take care of him, I love him, I never get angry with him, I always don't, when I'm angry with my child, I think I have this child, I will give this item, so I do it So I have to be responsible, I love him, if it's like I'm angry I don't have children.." (P3)

"..He might love me more.. because he is more,, even mom knows why I love him more, right, the term is a lot less.. he is not like his brothers, not like sick like this, we know,, so sometimes the family "I'm really spoiled"... well the reason I'm just saying,, she's only one woman, it just so happens that she's only a woman herself, of which three are boys.." (P6)

The love given by the family to children living with HIV will help meet the psychological needs of children. The child's feeling of security obtained from home will make the child less anxious, and the child in his development will assume that other people are like his family.

From the psychological aspect, the diagnosis of HIV/AIDS can result in sharing problems, both with the acceptance of one's own status as an HIV positive person and the acceptance of those

closest to him for his HIV positive status. In this condition at the age of children who do not understand the pain that is in their bodies, while they follow their parents' words to take medicine every day. In the current position, parents must always provide a sense of comfort, lots of attention, patience in caring for children, until it's time to prepare themselves to convey to children about their illness.

(Rahakbauw, 2016), said that individuals in dealing with stressful situations need a form of support from the people around them, in this case children with HIV/AIDS who clearly do not understand and know about their illness and in reality they must take medication regularly for the rest of their lives. So it is expected that the family has a sense of empathy, concern, and this causes a sense of comfort, peace, belonging and being loved.

Third Sub Theme (5.3) : Fulfiling the Laboratory Examination

Salah satu aspek penunjang adanya perawatan kesehatan pada ODHA anak adalah dilakukannya pemeriksaan laboratorium secara rutin untuk menunjang pengobatan. Hal ini diungkapkan oleh partisipan berikut :

"..It's been done at the puskesmas, me, my son, and my wife, their blood has been taken.." (P3)

"..Check all CD4, viral load too.. so take CD4, on viral load paper, check all complete blood.. so every 6 months the blood is taken.." (P6)

"..If here, viral load is usually done every 6 months or not once a year. So we can assess whether the child is compliant with ARV treatment.." (T2)

"..We have a blood viral load test to assess the success of ARV treatment. Usually every 6 months or not, once a year they are checked.." (T5)

From the description above, in terms of health services, health workers are very responsible for the health of children living with HIV by always reminding them to routinely carry out laboratory re-examinations every six months or at least once a year, viral load blood tests are carried out to assess the amount of virus after ARV treatment is carried out.

According to (Astari *et al*., 2009), HIV viral load test is a test used to measure the amount of HIV virus in the blood, while the amount of HIV virus in the blood is called viral load, which is expressed in units of copies per milliliter (mL) of blood. By measuring HIV RNA in the blood can directly measure the size of the virus replica. After starting ARV therapy, it is necessary to monitor the patient regarding the side effects and its response to therapy. Ideally, HIV RNA levels should decrease rapidly after antiretroviral therapy is started.

Conclusion

Lack of knowledge about HIV/AIDS by participants so that it becomes an initial obstacle faced by families of children living with HIV, this has an impact on the child's HIV status which is also late to be known early on, but in terms of child care, children get a lot of support, both from their own families and from the community. health workers, who with the support provided have an important role for the child himself.

Families also try to provide the best care starting with meeting all the needs of the child, meeting all the needs of the child, providing ARV treatment according to the dose given, and

conducting routine laboratory examinations every six months to monitor how the progress of ARV treatment that has been given to the child so that the child remains can live his life.

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