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FAMILY EXPERIENCE IN CARING SCHOOL AGE CHILDREN WITH HIV/AIDS IN SENTANI PUBLIC HEALTH CENTER JAYAPURA PAPUA

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ABSTRACT

The phenomena occurs in the community related to family care in children with HIV/AIDS is not all family members can accept and adjust quickly in caring of children with HIV/AIDS. The family will feel guilty, angry, tired and stressed-out facing the condition. This study purpose was to explore family experiences in caring of school-age children with HIV/AIDS at Public Health Center in Sentani, Jayapura Papua. The research design used a phenomenological approach. Data collection techniques were purposive and snowball sampling with semi-structured in-depth interview. Participants in this study were family (grandmother, aunt, uncle), with a total of six participants. Data analysis used the thematic Colaizzi's method. The study result had 6 themes as follows; feel scared of children illness with HIV/AIDS, feel the grieving's process; feeling confident about ARV treatment and prayer; personal hygiene care in children with HIV/AIDS; support obtained while caring children with HIV/AIDS; and the stigma developed in the community regarding HIV/AIDS. It was found that families who cared for children with HIV/AIDS are scared of the children's illness, feel the process of grieving, child's hygiene care and stigma that develops in the community. This study explained about family belief in ARV treatment and prayer having the same function and purpose, which was maintained the children with HIV/ AIDS to stay alive, the support obtained in raising children with HIV/AIDS. It is recommended that future researchers find the obstacles faced by families in caring of children with HIV/AIDS using the mixed method.

***Keywords**: Children with HIV / AIDS, family experience.*

INTRODUCTION

The researcher's initial informal interviewed with the informant (Grandma Y), as a family who cared for a child with Initial "A" as followed: **"i have been caring for my grandchild since the age of 18 months until now and he is almost 10 years. His mother died when my granddaughter was 7 months old because of being infected with HIV. My husband and i found out that our grandchild was infected with HIV in 2011".**

The other intial interview wwere taken with the informant (Grandma I), as a family who cared for a child with initial "I" as followed: **"i am the grandmother of a child with initial "I" and she is 11 years old, my grandchild started taking ARV in 2016 until now. My grandchild were infected with HIV from his mother, his mother had died since my grandson were 1 year old, and i knew that my grandchild were infected with HIV in 2016**"

Two informants stated that they had long cared for grandchildren with HIV/AIDS whose parents died due to HIV/AIDS. The research conducted by Ernawati (2013) found that most of HIV/AIDS children were not cared in an intact family structures. Six out of ten children are orphans, living with grandparents. According to UNAIDS (2010) Around 16.6 million children under the age of 18 had lost one or both parents because of AIDS.

The number of HIV/AIDS cases in Sentani Public Health Center in 2018 based on a voluntary testing counseling approach were 299 reactive patients, counseling initiate by health workers were 1,514 reactive patients. Its found from the numbers listed above, that there were 8 children living with HIV/AIDS has been taken care by their families, because their parents have died with HIV/AIDS. The majority of children living with HIV/AIDS are raised by their grandmothers. There are only two children who are still active in ARV treatment until now (Secondary Data of Sentani Public Health Center, 2018).

The number of HIV infections in Indonesia reported by the Province per December 2017 were around 280,623 HIV patients and the 10 biggest ranks were as followed: DKI Jakarta (51,981); East Java (39,633); Papua and West Papua (33,668); West Java (28,964); Central Java (22,292); Bali

(17,024); North Sumatra (14,891); Riau Islands (7,902); South Sulawesi (7,662); and Banten (6,915). The statistics above showed that Papua were the third ranked as the highest number of HIV nationally. And Sentani City is one of the districts of Jayapura as the capital of Papua. The number of HIV infection reported in 2017 in children aged less than or equal to 4 years were 901 patients, aged 5-14 years were 425 patients, and 15-19 years were 1,729 patients (Ministry Of Health Republic of Indonesia, 2018).

The period of school-age children is often referred to as middle age or latency, a time for new challenges. The cognitive power to think of many factors simultaneously provides the ability of school-age children to evaluate themselves and feel the evaluation of their peers (Potter et al., 2016). At this time, their understanding of knowledge and concepts of health, sickness and treatment can be taught, but usually they do not really understand the treatment that is done for the disease. This is a difficult challenge for families in terms of children's satus disclosured.

In fulfilling the child's psychic, the family must be able to create a safe situation for children with HIV/AIDS infection. Families are expected to be able to help children if they experience difficulties. Enabling a condusive environment in the family, can create a good atmosphere in caring for sick family members. One of the best places to care for children with HIV/AIDS is a home and environment that is surrounded by loved ones, where they are cared for by the person closest to them, making the atmosphere more pleasant and comfortable so that children with HIV/AIDS feel themselves not sick because of support from people who love him (Handajani et al., 2014).

Stigma is a bad view and is experienced by children with HIV/AIDS in social relations, this is very detrimental to the child's growth and development process. It is not easy to make children understand what is happening to them and it is associated with the stigma of the disease (Ahmad & Pramono, 2015). Parents' fear of stigma in the community, causes parents (mother) chose not to reveal the children's HIV/AIDS status even to the families who live at the same home (grandmother, uncle, etc.) and to protect children from their environment excessively. The task of the health worker can minimize the stigma in the community, by providing clear understanding and information to the community and accepting the condition of the child in terms of associating with their peers. An increasing the need for health services from the community, nurses must be able to meet these needs by carried out their roles and functions as coordinator, service provider, nursing planning, educator, advocate and reform agent both within the family environment, and in the community (Ernawati, Suryoputro, Mustofa, 2016).

Family knowledge in caring for patients with HIV/AIDS is something that must be considered. A study stated that family members felt that there were two other things that become a need: knowledge of what is HIV/AIDS, how to transmit, signs and symptoms of HIV/AIDS; and how to prevent it in the community. If the needs of nurses and patients' families can be met, it is very likely the failure rate in caring children with HIV/AIDS will be decreased (Ernawati, Suryoputro, Mustofa, 2016).

Kusumaningrum (2017) the concepts of Family Centered Care (FCC) according to the Association for the Care of Children's Health (ACCH) are (1) Dignity and honor; nurse practitioners listen and respect the views and choices of patients. Knowledge, values, beliefs and cultural background of the patient and family combine in nursing plans and interventions. (2) Sharing Information; nurse practitioners communicate and provide information that is useful for patients and families correctly and not taking side of patients and families. Patients and families receive information at anytime, complete, accurate in order to participate in caring and decision making (3) Participation; patients and families are motivated to participate in caring and decision making according to the agreements they have made. (4) Collaboration; patients and families are also included in the basic components of collaboration. Nurses collaborate with patients and families in policy making and program development, implementation and evaluation, health facility design and education professionals, especially in the provision of family care will build strength, help to make the best choices, and improve the normal patterns that exist in their daily life during the illness and undergo healing.

Based on the explaination above, it is necessary to explore descriptive qualitative phenomenology to explore understanding the phenomena that occur in the experience of families caring for children with HIV/AIDS by describing facts related to information obtained from informants regarding family experiences in caring for school-age children with HIV/AIDS through semi-structured in-depth interviews. Semi-

Structured in-depth interviews were conducted because the researcher wanted to gain an experience from each individual (a different perspective from each participant) regarding family experiences in caring for school-age children with HIV/AIDS. The researcher expected a new experience regarding the experiences of families caring for school-age children with HIV/AIDS. The information can be used as a basic in providing nursing services for families caring for school-age children with HIV/AIDS. Therefore, as an initial stage, researcher are interested in conducting a study on family experiences in caring for school-age children in Sentani Public Health Center, Jayapura Papua.

The purpose of this study was to explore family experiences in caring for children with HIV/AIDS at Sentani, Jayapura Papua Public Health Center.

METHOD

The design of this study used a qualitative method with a descriptive phenomenological approach. Taking participants in this study used a purposive method and snowball sampling. Data collection by semi-structured in-depth interview. There were 6 participants in this research process. This research was conducted on February - August 2019 at the Sentani Public Health Center, Jayapura Papua.

Participants in this study were determined based on the achievement of data saturation, with the inclusion criteria set by the researcher as followed: family or primary caregivers of school-age children with HIV/AIDS, who are caring for or accompanying children with HIV/AIDS for approximately 6 months, families in good health both physically, and mentally, family cooperatively participate in the interview, and willing to be a participant and willing to share their experiences. Taking participant will stop if there is data saturation. Data saturation is the state in which information is conveyed by the participants and did not provide additional new information. Data collection tools used were mobile phones, field notes, and interview guidelines.

Data analysis used Colaizzi's method with stages: making transcripts of questions, reading interview transcripts, determining keywords, looking for attachment to one category to another, grouping the themes of the interview results, and describing the themes resulting from semi-structured in-depth interview. The ethical test needed to conduct this research were obtained from School Of Health Sciences Jenderal Achmad Yani Cimahi and the number were 77/KEPK/V/2019. Information about the study was provided to families who cared for school-aged children with HIV/AIDS and taking written informed consent

RESULTS

The analysis results of semi-structured in-depth interview were conducted on six participants using the Colaizii's method and obtained 6 themes as followed: 1) Fear feeling of HIV/AIDS disease suffered by children, 2) Experienced feeling of grieving process, 3) Feeling confident about ARV treatment and about prayer, 4) Family care for personal hygiene of children with HIV/AIDS, 5) Support obtained during caring for children with HIV/AIDS, 6) Stigma that develops in the community against HIV/AIDS. The six themes will be explained as followed:

1. Fear feeling of HIV/AIDS disease suffered by children

Semi-structured in-depth interview in six participants. Five of them expressed their fear of caring for children with HIV/AIDS. Feeling afraid of caring for children with HIV/AIDS were expressed by participants including fear of caring, fear of how to care, fear of being infected when caring, feel afraid how to care when the first time the children were taken. The following statement 5 of 6 participants are as followed:

(P2) ***"when i first heard that my grandchild infected with HIV, i was weak, sad, scared. i was weak because I was shocked that my grandchild were small and could be infected with HIV, i was afraid that this disease could be infected, i was afraid to take care of her"***

(P3) ***"first time when i wanted to take the child to stay with us, i was very scared, i was afraid because my children were still small, i did not want them get infected with HIV from her, i was afraid of how to care for her, but if i did not take and care for her, who would she live with"***

(P4) ***"when the nurse told me the test results that the child were infected with HIV, i was weak, afraid, how could a small child get infected with HIV, i was afraid that the disease could not be cured, and could be infected, i was afraid to care for her"***

(P5) ***"when i heard the nurse say she was infected with HIV, i was weak, trembled, i looked the face of my grandchild, i was very sad and said ohhh dear .... she was so small and why she could get HIV, i was afraid how to care for her later"***

(P6) ***"the first time, we wanted to take and care for him, we both were afraid, but because the family refused to take care of him, we finally took and care for him, with the helped of the nurse we can now care for the child.***

2. Experienced feeling of grieving process

The results of semi-structured in-depth interview with six participants, three of the participants experienced feeling of grieving process marked by a rejection/ denial reaction. Participants revealed that the rejection/denial reaction that occurred and even till now still thinking that why is not adults were infected with HIV/AIDS. Feeling disappointed and cried why his grandchild were still small can be infected. Why small child can get infected with HIV. The following statement 3 out of 6 participants are as followed:

(P4) ***"until now, i still think why not adults who are sick with HIV, i asked God if she had to be born with this condition, so what for she was born, why small child could get disease like this"***

(P5) ***"i feel disappointed, cried, because of my grandchild were still small and got infected with HIV, i was sad and always think about her childhood"***

(P6) ***"we were sad, why did small child got sick with HIV, but maybe God gave this child to be present in our midst, so we can also love and care for him"***

3. Feel confident in ARV treatment and about prayer

Semi-structured in-depth interview with six participants, most of the participants expressed confidence in ARV treatment. Participants stated that the belief in ARV treatment was that if the child did not take ARV, he/she would die. Always advise children to be diligent in taking medicine to stay alive. Advise children to continue taking ARV drugs. If they do not take ARV in one or two days, they can become more ill than now. Following are the statements of six participants:

(P1) ***"she took medicine at 6 am and 6 pm, she could not swallow one pil at the beginning, i pounded it to make it like a powder. I said you should know that the medicine can make you well, if you do not take medicine, you will die"***

(P2) ***"She took the medicine regularly from the beginning until now, i always said he had to be diligent in taking medicine, because the drug gives her long immunity"***

(P3) ***"The child with initial "S" took medicine at 6 am and 6 pm, she knows the time of taking her own medication, but i always tell her to be diligent in taking medicine to stay healthy"***

(P4) ***"The child with initial "M" took her medicine at 6 am and at 6 pm, she took medicine regularly but must be monitored, if she did not take medication 1 - 2 days she could get sick more severely from now, so she must not neglect taking medication"***

(P5***) "The child with initial "F" took medicine at 6 am and at 6 pm, she took it regularly from the beginning, i always said she has to be diligent in taking medicine to stay healthy and growing to she will be a successful person"***

(P6) ***"The child with initial "R" diligently took medicine at 6 am and at 6 pm, the nurse said the drug was to increase the immunity, so he had to keep taking medicine to stay healthy.***

4. Family care for personal hygiene of children with HIV/AIDS

The results of semi-structured in-depth interview with six participants, three out of six participants revealed that the child was diligent in taking bath, that the ability to care for the child's personal hygiene with HIV/AIDS were diligently taking bath in the morning, afternoon and evening, if the child did not bathe would appear scabies on all parts of the body, bathing using soap, brushing teeth, tongue brush if you do not brush your tongue will appear white fungus in the mouth, always use shampoo to wash your hair every day if you do not use shampoo will appear fungus such as dandruff on the head, after bathing change clean clothes. Following are the statements of three out of the six participants:

(P1) ***"The child with initial "I", bathed diligently, took a warm bath in the morning and evening, took bath using soap, brushed teeth and tongue, if she did not brush her tongue the white fungus appeared in the mouth, she always washed her hair using shampoo every day. Changed clean clothes"***

(P3) ***"she diligently bathed in the morning and afternoon using bathing soap, brushed his teeth, washed his hair, changed his clean clothes. The morning before going to the school she had bath, came back from school at noon time she had bath, early evening she had bath too"***

(P6) ***"he diligently had bath in the morning and afternoon using bathing soap, brushed his teeth and mouth, if he did not brush his teeth***

usually appeared white fungus on his tongue or lips, every day he had to wash his hair if not washing his hair would appear like dandruff on his head. Changed clean clothes"

5. Support obtained in caring for children with HIV/AIDS

The results of semi-structured in-depth interview with six participants in different statements, most of participants stated that the forms of support received were information, emotions and social. Following are the statements of six participants in different questions:

(P1,2,3,4,6) **"*the family said that they still take medicine well, eat well, rest well. The Pastor always came to pray and delivered donations from the church to the sick patient. Health workers always made a home visit to monitor the condition of the child with initial "I", delivered medicine, sometimes brought milk"***

(P5) ***"pastor often came to pray with both of us. Nurse always came home to monitor him and delivered medicine for the next month"***

(P1) ***"i gave her advice, i said if you want to be healthy then you have to take medicine and eat regularly"***

(P2) ***"i gave her advice, i said you had to take bath diligently so the wound will be cleaned, the wound could heal quickly, i said he had to keep the spirit of taking medicine to stay healthy"***

(P3) ***"i gave her advice, diligently taking medicine, diligent bathing, eating well, resting on time***

(P4) ***"i said he had to be diligent in taking medicine, not to be lazy. Stay patient, cheer up, so he can stay healthy"***

(P5) ***"i gave her advice, i told her to come home early when playing at her friend's home before it gets dark. Come home early, take a shower, eat and take medicine on time"***

(P6) ***"gave advice that he must be patient, keep the spirit to take medicine, because by taking medicine every day you can stay alive"***

6. Stigma that occurs or develops in society/community against people with HIV/AIDS

Semi-structured in-depth interview with six participants. Five out of six participants revealed that they still close the status of the child. Its only known to close family, certain people, participants, children who know the status of children with HIV/AIDS. The following are statements of five out of six participants as follows:

(P1) ***"i still closed her status, i am afraid that many people will keep distance from her like his mother"***

(P3) ***"i still closed her status, i am afraid of family and neighbors, they will keep distance from her if they know about the disease"***

(P4) ***"i still closed her status. The family did not know about the disease so far, they thought her had lung disease, they did not know she was infected with HIV"***

(P5) ***"i hid his illness from people, i am afraid that if they know they do not want to approach her, especially school friends and playing friends near by home, other people also will avoid her, its only pastor and her who knows about her illness"***

(P6) ***"we hid his HIV status, other people did not know that he is infected with HIV, they only know he has lung disease, its only close relatives who know he is infected with HIV"***

DISCUSSION

1. Feeling Fear of HIV/AIDS experienced by children

Fear is a situation where the individual can not calm down in dealing with emotions that flare up on himself/herself, for example anxiety, nervousness, worry, feeling very scared, alert, uneasy horrified (Hardani & Hardayanti, 2017). Feelings of fear of caring for children with HIV/AIDS experienced by families due to lack of knowledge and understanding of HIV/AIDS and fear of get infected (Marsito & Saraswati, 2016; KBBI).

This research explained that people who have enough knowledge about risk factors, transmission, prevention, and treatment of HIV/AIDS tend not to be afraid of PLWHA. The level of one's understanding of a matter is largely determined by the knowledge he has acquired and his cognitive abilities. This knowledge is received through various sources such as education, training, family environment, community and social service institutions. Caring for people with HIV/AID, the first thing a family needs to do were understood correctly about HIV/AIDS, so that they could treat patients well and protect themselves (Rahakbauw, 2018; Morgan, Maramis & Ratak, 2018; Haluhiya et al., 2015).

Knowledge has a large and positive influence in caring for children with HIV/AIDS. When families cared for children with HIV/AIDS had broad knowledge and understanding of HIV/AIDS,

it can provide a positive understanding of the care of children with HIV/AIDS without the fear of get infected. So that children living with HIV / AIDS in the family environment received care as healthy children, feel comfortable, feel accepted, feel as an integral part of the family, this will greatly help the growth and development and health of children who had HIV/AIDS.

2. Experienced Feeling of grieving process

The findings in this study revealead about feeling of grieving process including rejection/denial reaction. Participants stated a rejection/denial reaction that occurred and still thinking till now that why were not adults get infected with HIV/AIDS. Feeling disappointed and cried why his grandchild were still small could be infected. Why small children can get infected with HIV. The sad feeling expressed by the patient were feeling sad whether the child will live or later die, very sad and asked God why the child had to be born with the condition like this, feeling sad how about his childhood.

Grieving is a total response to emotional experiences due to loss. Grieving is manifested in thoughts, feelings and behavior related to distress or deep sadness (Mujahidah et al., 2015). The process of grieving consists of five stages as followed: denial, anger, bargaining, depression, and acceptance. Children diagnosed with HIV/AIDS will experience changes in health and cause a grieving reaction both for children and for all family members (Lahariani, 2017).

Research conducted by (Ristriyanti, Rachmawati & afiyanti, 2018; Lahariani 2017; Vitriani, Sitorus & Afiyanti, 2017) that the grieving reaction shown to the disease were: first were denial/rejection. Individuals display denial, distrust, shock, this happens when they were diagnosed, and sometimes they projected their emotions by blaming that there were a mistake in diagnosing.

The task that must be carried out by families who experienced a grieving process is to be able to accept the reality of children HIV/AIDS disease and be able to adjust to the environment. In this case nurses need to understand the concept of the grieving process and the factors that influence it, they have to be able in facilitating a proper grieving process and in providing nursing services for families cared for children with HIV/AIDS.

3. Feel confident in ARV treatment and in prayer

The findings in this study revealead the feeling confident about ARV treatment and about prayer. Participants stated that the belief in ARV treatment were if the children did not take ARV, they would die. Always advised children to be diligent in taking medicine to stay alive. Advised children to continue taking ARV drugs. If they do not take one or two days, they can get more ill than now. The belief in worship and the power of prayer, participants revealed teaching children to pray, and diligently worshiping because by praying to God, participants felt confident that children who had HIV/AIDS could be cured with miracles according to God's timing.

Belief according to the KBBI is trust, certainty, serious determination. And religious belief is a tangible part of the concept of belief of its adherences. Belief makes respondents have the view that they were able to deal with conditions with positive status with HIV/AIDS. Getting closer to God is also the thing that respondents do to be able to face the conditions experienced. Faith in yourself always has to surrender everything to God. Respondents assumed that behind the belief there must be still an effort to do such as to worship, pray, and continue ARV therapy (Putri & Tobing, 2016).

Spiritual played an important role in the treatment of HIV/AIDS. Research on the importance of spirituality in chronic diseases including HIV / AIDS has been carried out. This other research were conducted by Aziza (2018), that by giving only ARV without prayer therapy indicated that the average CD4 levels of HIV/AIDS patients before and after being given ARV therapy were the same (no different).

Belief in ARV therapy and belief in prayer have the same function and purpose, which is to maintain the lives of children who have HIV/AIDS to stay alive. And the family plays an important role to remind children to take ARV according to the time recommended by health workers. And the family also plays an important role in the child's spirit to generate positive thoughts in children, making children stay excited through the days of his lfe.

4. Family care in caring for personal hygiene of children with HIV/AIDS

The findings in this study revealead about family care in caring for personal hygiene of children with HIV/AIDS. Participants stated that the ability to care for the personal hygiene of children with HIV/AIDS were a child who took bath

diligently in the morning, afternoon, and early evening, if the child did not bathe will appear white fungus on all over parts of the body, took a bath using soap, brushed teeth, brushed the tongue if its not tongue brushed will appear white fungus in the mouth, always used shampoo to wash hair everyday if its not used it will appear like dandruff fungus on the head, after bathing changed clean clothes.

Personal hygiene is one of the efforts to improve health. Personal hygiene is very important and must be considered in everyday life, because cleanliness will affect one's physical and psychological health. Children with HIV/AIDS are susceptible to disease. Lack of knowledge and awareness of the family in paying attention to children's personal hygiene also causes children not to pay attention to their own hygiene. And it has a potential to cause health problems, such as skin diseases will be easier to attack (Kusmiyati, Muhlis & Bachtiar, 2019; Ali & Yusuf, 2015; Ardhiyarini, 2008).

Other researchs (Ali & Yusuf, 2015; Istianingsih, Yamin & Ilyas, 2014; Triasmari & Kusuma, 2019) explored that children's personal hygiene must be maintained as early as possible to avoid diseases caused by lack of self-care as followed: cleanliness of skin health, skin is the outermost layer of the body in charge of protecting the underlying body tissue and other organs against injury, the entry of various kinds of microorganisms into the body. Therefore, its need caring for skin health and hygiene. Maintaining skin cleanliness and skin care aims to keep the skin in order to stay well maintained and protected so that it can minimize any threats and disturbances that will enter across the skin. Dental and oral hygiene, children's dental and oral health can affect the child's development and learning process.

The role of families in caring for children with HIV/AIDS were very important in monitoring the personal hygiene of children who had HIV/AIDS, so that children avoid various kinds of disease problems that will arise due to lack of personal hygiene. The role of the nurse were very important in this case by providing counseling about personal hygiene in order to increase family or caregiver knowledge. In addition, the role of health workers needs to be improved by giving a counseling to enhance knowledge of family in caring personal hygiene conditions for children with HIV/AIDS

5. Support obtained in caring for children with HIV/AIDS

The findings in this study revealed the support obtained in caring for children with HIV/AIDS its a form of support. Participants stated forward the forms of received support were information, emotions and social. The sources of support obtained from families, pastors, and health workers.

According to KBBI says that support means support or assistance provided. Support obtained comes from the government and the community, an important role besides the government and the community were the family. The family is the smallest unit in the community which were defined as consisting of father, mother, children, aunts, uncles, nephews, grandparents, grandmothers and even adopted children (Rakhabauw, 2018). Children living with HIV/AIDS needed support in fulfilling children's rights> Regulations governing children's rights for rights to survival, right to protection, rights to growth and development, and rights to participate as stated in the Convention on the Rights of the Child (Wachdin, 2016).

Other researchs (Rakhabauw, 2018; Rahmawati & Suwandi, 2019; Yasmin, 2017) that individuals who faced stressful situations require a form of social support from those were surrounded them. The form of social support and from whom the support requires also varies from one individual to another.

Family support, support of health workers, support from the pastors, and support from community social services were very important for families in caring for children with HIV/AIDS. With the support received by the family from various sources, it could increase family knowledge in caring for children with HIV/AIDS. And the families were able to provide maximum care to children who had HIV/AIDS, so the children who had HIV/AIDS can grow and develop as healthy children. Children or family members who had infected with HIV/AIDS must be treated as human beings with dignity, because positive acceptance and treatment from the family will greatly help overcome external and internal pressures. Providing support for the lives of PLWHA to live in positive and meaningful life. Institution services for HIV/AIDS is as the frontline in providing assistance to the community, especially PLWHA, in order to treat them without differentiating them from others. Hold regular meetings and activities that support social life for families and PLWHA. Improve coordination and cooperation with the community

and religious leaders in spreading information about HIV/AIDS by Social Worker of Education Institutions.

6. Stigma that occurs in society against people with HIV/AIDS

The study revealed the stigma that occurs in the community against people with HIV/AIDS were included of closing the status because fearing of children being shunned by the environment, family, social and community. Participants revealed that they were still closing the children' status and its only close relatives, certain people, participants, and the children who knew the status of children with HIV/AIDS. Curse disease that is very frightening for many people and expressed by participants that its a curse disease that is feared by many people, including the participants themselves, everyone will avoid and stay away if they know the status of the child.

Stigma is a negative trait given by society and influenced by the environment. This negative characteristic is given to people who are considered disabled, dangerous and somewhat lacking with others in general (Situmeang, 2017). The three main concepts that make up understanding stigma are linked to groups of children infected with HIV: associative stigma, internalization stigma, and stigma management. Associative stigma is due to the association of individuals with stigmatized people. The stigma of association affected families or caregivers who cared for children with HIV/AIDS, or affects children whose parents had died of HIV/AIDS. Children will be associated with stigma if opening their status is linked to being HIV positive (Syahrina & Pratana, 2018).

According to other research (Gobel & Idris, 2018; Zakaria et al, 2018; Achmat & Pramono, 2015; Syarina & Pranata, 2018; Carsita, 2018; Karamouzian et al, 2015) conducted in Indonesia by Butt in 2010 in Papua revealed that of all respondents were only a few people revealed their positive HIV status to one of their closest relatives. Because they were worried about the stigma that emerges like HIV/AIDS is considered a curse from God, ancestors who had died or jinn. HIV/AIDS is considered as a frightening and deadly disease so that people who experience HIV/AIDS will be avoided by families and the wider community in general.

The statement above were proportionate to the participant's statement. Participants in this study said that the children' status were still closed because of fearing of children being shunned by the environment, social family and society. Participants revealed that they were still closed the status of the child, and its only the family and the closest person knew the status of the child. HIV/AIDS is also seen as a very frightening curse to many people, including the participants themselves.

CONCLUSION

Based on the results of research on families caring for children with HIV/AIDS, six themes were found in caring for children with HIV/AIDS as followed feeling afraid of HIV/AIDS suffered by children, Experienced feeling of grieving process, feeling confident about ARV treatment and about prayer, family caring for personal hygiene of children with HIV/AIDS, support obtained while caring for children with HIV/AIDS, stigma that developed in the community against HIV/AIDS. Each of the six themes were divided into categories and has been explained above.

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