

Role of Family on HIV-AIDS Children Who Are Getting An Antiretroviral (Arv) Treatment In Indramayu District: A Phenomenography Study

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ABSTRACT: The condition of children infected with HIV cannot be separated from the HIV status of their biological parents. The biggest pressure faced by parents is the fear of what they have done will be in vain. Parents knowingly know that there is no vaccine that can eliminate the HIV / AIDS virus from the bodies of these children. ARV (Antiretroviral) drugs consumed by children every day, only serves to reduce the number of viruses to develop. This is what makes parents sometimes drop out of hope in raising children infected with HIV / AIDS, not to mention the openness of the child's status which is a burden on parents in giving answers to their children's questions, because of boredom and boredom towards treatment regimens that is done every day continuously. Same is the treatment that is carried out regularly every month which requires a family economic burden so that the dual role of a mother must help her husband work to increase the family's economy. The purpose of this study is to know about the role of families in caring for HIV-AIDS children who are getting treatment antiretroviral (ARV) in Indramayu Regency. Method: This study uses descriptive qualitative phenomenological method with semi-structured interview technique with eight respondents. Data analysis used by Miles and Hubberman models. The results showed that the role of the family was very influential on the respondents reflected in four themes, namely 1) the role of the family towards the acceptance of the disease status of children with HIV / AIDS, 2) the role of the family in the spiritual function of the disease of children with HIV / AIDS in their beliefs to recover, 3) the role of families in the economic problems faced by children with HIV / AIDS during treatment, 4) The role of the family in the openness of the status of children with HIV / AIDS. Conclusion Family as the main support system is needed by PLWHA to develop effective coping and adapt to stressors related to the disease.

Keywords: ARV (antiretroviral) treatment, family role, HIV / AIDS child

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I. Introduction

HIV infection is a chronic disease that requires life-long treatment. People with HIV / AIDS (PLWHA) are required to consume ARV (Antiretroviral) every day and on time, by maintaining their food intake and maintaining the rhythm of their daily activities. Families with children with HIV / AIDS (ADHA) who have to undergo ARV treatment therapy for life can experience a phase of boredom in carrying out treatment by stopping taking medication so side effects such as opportunistic infections occur and the burden will not affect the family members. All of these conditions require good support and motivation in the family, if the HIV status is known by the family, the impact will be good on relationships between families. Parents generally feel guilty or feel anxious because they feel responsible for what happened to the child, or in their sadness they hope to replace the child to bear the HIV / AIDS acquired from him. Parents need sympathetic help and support from all parties involved, both for the welfare of parents themselves and for their efforts to provide care for the child (Sunaryo, 2004; Friedman, 2010) says that the health care function is a function to carry out practice health care, namely to prevent health problems and treat sick family members.

Some parents feel stressed caring for their children who suffer from HIV / AIDS. They will find it difficult to understand the feelings and conditions experienced. Ignorance of family financial needs and care and social life also affects psychologically and physically parents especially mothers in caring for children with HIV / AIDS

Families especially mothers will face challenges in accepting and adapting to their children such as distrust, changes in the lifestyle of mother and family and financial stress. In addition to adapting to the condition of the child, the mother also struggles to be able to face the pressure of undergoing treatment and confusion in facing the future and development of her child. The role of mothers in development is very important, because with good mother skills, it is hoped that child monitoring can be done well. Parents (mothers) are the first people who invite children to communicate, so that children understand how to interact with other people using language. Environment (family) is one of the factors that influence children's growth and development (Hidayat, 2006). Lack of the mother's role in fulfilling the child's basic needs certainly has an adverse impact on the child's development itself. If the role of the mother is not successful, the child will experience growth and development disorders and if the child experiences delays in growth and development, it will be difficult to detect and if the mother's role is successful, the child can grow and develop according to his age. This makes the role of a mother very influential in child development, especially in children with HIV / AIDS, because of the differences that will be felt by children after adolescence, where they feel different from their peers, as well as routinely taking drugs continuously and this will be a constraint on the role of a family, especially parents in providing clear knowledge and information so that children understand the conditions they are experiencing.

Research conducted by (Nsheha, 2014) shows that ADHA that successfully adheres to the treatment regimen is able to survive to adolescence, while children who do not adhere to the treatment regimen increase the risk of virology failure and viral resistance. When a child with HIV starts to do treatment, the family or caregiver must prepare themselves in advance to begin treatment so that the impact of treatment can be dealt with and thus the quality of life of the child is guaranteed. ADHA compliance (Children with HIV / AIDS) is a special challenge which is a relationship of three factors, namely, child, parent or caregiver, and medication. Some other factors that influence compliance problems include consuming inadequate doses, too many pills, children who do not want to take medicine either in the form of syrup or in the form of quail because of the unpleasant taste and side effects of the drug. weak children, distant health facilities, and very expensive drugs, (WHO, 2010). In the condition of children with HIV / AIDS, the role of the mother is needed in carrying out the child's daily routine, so that the child will not feel burdened by having to take medication everyday. The role of the mother in fulfilling the basic needs of children is grouped into 3, namely: needs for caring, nurturing and teasing. Care needs in fulfilling physical needs include giving love, attention, security, warmth to the family so that they grow and develop according to their age and needs. Fostering needs in meeting emotional needs or affection include meeting the needs of child care and care so that their health is maintained, so that they are expected to be healthy children physically, mentally, socially and spiritually. Teaching needs in fulfilling mental stimulation include meeting children's educational needs, so that they become independent children in preparing for the future (Anime, 2011)

Teaching, compassion and nurturing needs given by parents to children with HIV / AIDS have an impact on their growth and development. Children will grow physically, psychologically and socially in the child's future. If this need becomes an obstacle to the role of the mother, in particular, the impacts such as physical, psychological and social disturbances can be hampered. Efforts to overcome problems that arise in children in hospital care efforts, focused on nursing interventions by minimizing stressors, maximizing the benefits of hospitalization and providing psychological support to family members (Wong, 2009). When children suffer from chronic diseases such as HIV / AIDS, the duties and responsibilities normally faced by a mother will increase and will likely make it difficult for other family members to deal with it normally. Because of changes in conditions, the mother as a human being must be able to adjust to a life that changes in her family as the interaction between body, spirit and environment (Sunaryo, 2004). Mother is unable to fulfill all of her children's needs independently in terms of cost, support, energy and information fulfillment. Therefore, the mother will look for those who are considered capable of providing assistance. The family is the person closest to being asked for help, but not all can be expected to provide assistance because each family has their own stress and economic limitations as well. The results of the study (Naik, et al, 2009) said that costs (75%) were the biggest obstacle that prevented them from routinely undergoing treatment at health facilities, because the distance conditions that did not allow them to routinely seek treatment every month at health facilities. Cost is one of the factors causing non-compliance of PLWHA in treatment because it takes a long time with the consequences of the costs to be incurred, including the cost of laboratory examinations and treatment of opportunistic infections that are developing, so that many PLWHA must seek loans or sell valuable assets. High financial needs will encourage families to also feel the changes in the wheel of economic rotation, therefore the support of families in financial matters greatly helps PLHIVs in alleviating the burden of medical expenses that are so great.

Financial support is also a form of support that is very helpful for PLWHA in terms of drug financing, costs for travel and eating while in the health facility. This can reduce the stress of PLWHA and indirectly, he can find solutions to problems related to finance. Research results (Basanti & Nomathemba, 2010) illustrate that one of the support needed by people with HIV / AIDS (PLWHA) to undergo treatment is financial support because they do not have a job, the high cost of treatment and care. So this is the existence of the role and function of the family in relation to good economy that can support the success of PLWHA in living their lives well especially in terms of their adherence to ARV therapy treatment In the study (Li, 2009) it is also known that people living with HIV / AIDS desperately need help and support from families because this disease is chronic and requires comprehensive treatment The same thing was stated by Miler (2004) that the impact of chronic diseases does not affect the mother alone, but the whole family in it. If one family member suffers from a chronic illness, the family is indirectly in a chronic condition.

II. Material And Methods

The purpose of this study was to explore descriptive qualitative phenomenography to explore and understand the phenomena that occur in "the role of families towards HIV-AIDS children who are receiving antiretroviral (ARV) treatment in Indramayu district", so that the most fundamental obstacles in the family's role in doing ARV treatment in children with HIV / AIDS This study was conducted on eight respondents with ADHA (children with HIV / AIDS) in the Indramayu district. Samples were taken purposively, including; a) The main family or caregivers of 6-12 year old school children with HIV / AIDS who are on ARV treatment, and at least have treated or accompanied children with HIV / AIDS for more than 6 months. b) The family is in good health physically, mentally and cooperatively during the interview, c) Being able to understand Indonesian, d) Willing to be a participant and willing to share his experiences. The techniques used are semi-structured interviews with data analysis of Miles and Huberman.

III. Result

Participants in this study were aged between 30 years to 67 years. Characteristics of the level of education of parents or caregivers vary from not graduating from elementary school (SD), graduating from elementary school, not graduating from junior high school, graduating from junior high school. Characteristics of the types of work of the participants also varied ranging from unskilled workers (construction workers), housewives and prostitutes. Eight (8) participants came from Indramayu native people and they could speak Indonesian well and clearly. The age characteristics of children with HIV have an age range of 6-14 years. Characteristics of sex include 7 women and 1 male. After the data has been reduced, then the data is presented so the next process reduces data to obtain the following themes: The first theme is The role of the family in receiving the status of the disease of children with HIV / AIDS. This theme was obtained when

participants had to retell the situation at the beginning of the child being said to have HIV positive, the participants' feelings seemed sad, crying and as if they did not believe that their children also had to suffer the actions of their parents. But that does not make them worse off by the situation, they struggle until their child can return to normal life like other normal children. The following statement

"... after knowing that my child was hit by this virus it felt like the world was about to collapse ... it couldn't be imagined ... didn't believe it ... it was a mixed jumble ... the doctor gave a verdict there was no hope ... but my child was strong ... that makes me strong ... I'm looking for all the information and I keep on counseling with my wife. (P4) "

"My feelings were raging, it hurts so much, huh, it was mixed ... sad ... as a result of me he became so rich ... I loved it ... how did this child have to stay alive ... I can't be sad ... let God just reply ... (P3) "

... the principle is only one, a child who makes us survive, so that he is left with his mother, but I still feel he is like my child ... I follow what the doctor said (P7) "

The same response was experienced by other participants, the response did not believe the same as the participants said before, but participants always sought information by listening to counselors about HIV / AIDS as the following statement:

"... who must have been shocked, sad, ruined by no means as if I didn't believe that a child as young as 2 or 3 months old had been infected with HIV ... after being told, I realized he was given breast milk after birth ... I didn't know at first ... (P1) "

The same thing raised anxiety in the participants as a response to a disease that could be a stressor because of uncertainty in life, but participants believed that their great confidence in the recovery of their children was shown by the participants below:

"... it's my feeling, it hurts, it hurts ... it's a variety ... it's mixed ... it's sad my child can live a rich normal child no longer ... until I can't sleep ... I can eat but how about Yes, it's fate ... I pay attention to it, eat it ... drink the medicine so that it doesn't drop again ... (P2) "

The next response is the anger shown by the participant with disbelief and self-blame which is considered to have infect his child, as stated below:

"My feelings were raging, it hurts so bad, so mixed it feels ... sad ... afraid of how my child is in the future ... until I can't sleep I can't eat, but how about it is fate, I want to think about it too fate ... (P3) "

The second theme is The role of the family in the spiritual function and belief in recovery. Finding help here is illustrated by two themes, namely changes in spiritual patterns and designing the future. Changes in spiritual patterns are manifested in the form of closeness to God through submission, repentance and prayerful behavior, as stated below:

"At first I was resigned to destiny, but God willed my child to survive ... still alive until now ... maybe I study him to pay, pray so that his life is better than his parents ... (P1) "

"I told my child to take part in a prayer here ... so I can pray, praying and praying together with Allah's gusti to recover ... his life is good, not rich in his mother ... (looks down and covers half of his face) (P2) "

"I often pray for the gusti Allah, hopefully my child is healthy and not like my fate ... (P3) "

Attitudes Family caring for the child's future is very visible in the child's situation, the family, especially parents here are very concerned about the health of the child by complying with the treatment regimen, because of his belief in the recovery of his child, and can be like any other normal child, such as the participant's statement below:

"... Even though life like that can still live healthy, you can do something like other children, ... (P1) " ... " ... Hopefully there is a cure for it, and it doesn't drink every day, so that its future is bright (P3) "

Expectations for assistance from the Government that make parents try to recover their children and confidence in the future of their children, such as the following statement:

"... The hope is that the government continues to pay attention to children with HIV / AIDS who have the right to live healthy, the right to get education later also get a job (P1) "

With the BPJS assistance program (Health Insurance Agency), participants felt helped in terms of ARV treatment, as stated below:

"... there is luck that there is government assistance ... JS ... JS ... so it's not hard to take care of it ... BPJS..maklum neng ... (P8) "

In its spiritual function and belief in recovery, it is the path taken by the participants in the matter of repentance to leave events that have made themselves and their families bear the burden of their own actions according to (Schoenbeck, 1994 in Potter & Perry, 2005) saying there are four things that are recognized as a spiritual need that is the process of finding new meaning in life, forgiveness, the need to be loved and hope. The process of finding new meaning is a unique process and is not easy because it will cause stress and feelings of anger, feelings of regret or feelings of guilt. Support from the closest person, the family that makes parents have to convince their children to go a better way, so that they do not fall into actions that can harm him or his family, so learning religion makes children grow and develop better

The third theme is The role of the family in the economic problems faced during ADHA treatment. In the limitations, there are two themes, namely economic limitations. In the economic limitations there are several participants who work to help their husbands, this is the obstacle for participants in caring for their children who are on ARV treatment, such as the statement below:

"... the problem is having to go there once a month and continue to charge for eating there ... so I am forced to pay off, so I like to be ready next month ... most dictated ... (P1) "

"If there is money to seek treatment if I'm not forced to sell cakes, but it's not here, because if they know I'm the sales person, anyone wants to buy it later ... on fear of contracting it ... (P3). "

Unlike the previous participants, because there were 2 participants who were still working as prostitutes, working outside the city so that their children were entrusted to their grandmother, this made the child's condition sometimes not compliant with the treatment regimen

"... if the big one usually yells asking for medicine ... because once the forgetfulness drops immediately, that's why now using an alarm sometimes he has seen the clock first screaming for medication ... sometimes his grandmother also takes medication if I have money. Which hospital person would like to know about our condition ... the way we seek treatment must be on time ... (P5) "

"My husband is only a construction worker if he has money, he is treated but he likes to be angry ... but now he is not very rich anymore. I started taking care of my children in the beginning ... the baby is sometimes nitipin money but rarely ... (P8) "

The different circumstances experienced by the following participants, the form of concern of the surrounding community towards the participants by providing assistance for treatment of their grandchildren ... a empathy attitude that the community gives to this family so that the economic needs in caring for their sick grandchildren can be accomplished, as the following statement:

"... those who support me sometimes from being there, the recitation mothers like to come here, give money, say, to help treat my grandchild. (P6)".

"... if there is no help from the community here maybe ... this child is dead neglected ... because I myself am old ... I am not working ... (P7)"

Also economic assistance felt by participants in caring for children with HIV / AIDS comes from families, parents and siblings, they provide material and moral assistance, because of the mother's helplessness in fulfilling the economic needs of the family besides being faced with the condition of her disabled child, so she cannot leave her child with someone else, like the following statement:

"... I didn't work ... the color of my mother also forbade me from working ... just take care of your child ... let the mother help you eat and medicine for your child ... (P4)".

Economics is very sensitive to the lives of participants, with economic limitations and confronted with conditions of chronically ill children (HIV / AIDS) this worsens the family's economy. This is a challenge and obstacle experienced by all participants, but they still struggle in living the wheel of their daily lives, because of their strong determination and motivation for their child's recovery, for their future, parents are willing to sacrifice themselves to change their role, especially the mother figure in terms of helping family economy so that children's needs are sometimes not fulfilled optimally, but this does not make them lose hope for their child's recovery.

The fourth theme is Openness of status of children with HIV / AIDS. The status of children with HIV / AIDS which has become a major fear is faced by several participants. The families, especially parents, choose not to disclose the condition of the child's illness with the reason that young children do not understand anything, but their biggest fear is in facing stigma in the community, as follows:

"After returning home from school because it was so tired ... it rarely played, most of the time I played at home there was a friend who played ... I haven't told you yet ... I ask why do you take medicine ... the friends don't take medicine. (P2) ".

"If the neighbors know the richness, I just haven't told my child yet, because he is shunned by his friends ... (P3)".

The different things that participants face and the openness of their status makes them feel ashamed of their children, and there is a hope not to follow their mistakes and parents are able to deal with situations like this, their children accept their status (there is no problem in the child), as follows his statement:

"The biggest thing is that I already know because it's already junior, I already understood ... at first, he didn't understand ... I intentionally let him know so he won't be rich in the future ... (P5)"

This participant's openness attitude is very supportive of the programs provided by counselors, so with the information and knowledge about HIV / AIDS can help parents in caring for children with HIV / AIDS, so that the obstacles faced by children in the community can be prevented. The form of social support received by the family in the form of information support from health services. The information support provided can reduce the community's stigma towards family and children during ARV treatment, the following statement below:

"As I have read and I have obtained from counselors or doctors, if you are sick like this, you will not get infected with each other or shake hands ... so they now understand (P1)".

The openness of participants to the condition of children with HIV / AIDS to families makes parents ready to accept the conditions they will face in the future, such as the following statement:

"People already know everything, they are sorry. Maybe they know that I'm only a contagious victim from my husband ... (P3) ".

"... The family at first did not know after I told them at first that they were scared, all the eating utensils were separated but my mother said it could not be separated! ... I was moved. (P4) "

Community stigma that arises due to lack of understanding, lack of information and lack of public knowledge of family conditions with children with HIV / AIDS. It is the role of health care workers who must stand in front of them in the face of stigma in society. Information and sufficient knowledge of modes of transmission and prevention can reduce people's fear of children with HIV / AIDS.

IV. Discussion

Based on the results of research on the role of families in children with HIV / AIDS who are on ARV treatment, 8 participants said that the role of the family is so complex that they live in caring for children with HIV / AIDS. In 8 participants experienced the same thing when they first learned about the condition that their child contracted HIV / AIDS from him. Feelings of sadness, disappointment, anger, do not believe all they have gone through, which is not easy for everyone to do, because of the support from their families and closest people and children who motivate him to rise up, fight against this disease.

In general, someone diagnosed with HIV will experience psychoklogical effects such as stress, rejection, distrust, anger and suicidal desires (UNICEF, 2009). From the results of this study in general, feelings of sadness were experienced by participants. This is due to a discrepancy between expectations and reality experienced by mothers and families due to illnesses suffered by their children (Kozier et al, 2004). Participant 1 until they do not believe the newborn child has to bear the burden due to the mistakes of his parents and must bear the burden during his life, it is seen when in the interview there is an emotional feeling and depression (anger, stress and crying) experienced by the family

In people living with HIV with a positive HIV infection stage, physical conditions that are unstable and tend to decline followed by the emergence of physical symptoms along with the course of illness and social pressure that is so great obtained from the environment can be a source of stress that can cause PLHIV to experience depression (Kusuma, 2011).

Depression is the hardest phase experienced by participants. Conditions where it is difficult to accept the reality that has occurred. This phase of depression shows that participants feel sadness. Acceptance of having a family member diagnosed with HIV / AIDS is when participants surrender to God. Participants believe that the circumstances that occur are destined to be lived and believe there will always be meaning and wisdom behind each event. The belief of PLWHA to be cured requires good religious knowledge and in terms of relationships with the Creator, where he must be sure of the healing given by God Almighty. As illustrated by the attitude of participant 6, in this case the role of the family is replaced,

especially the figure of a mother turning to her grandmother, which will be a change in the role of the mother that influences the growth and development of children.

Bringing a sick family member to a health facility is a duty and family responsibility including choosing the right health facility (Friedman, 2010). However, not all families will provide good facilities for sick family members by providing eligibility during treatment, because the burden of medical expenses that are felt so large will have an impact on the family's economy. This was shown by 2 participants who were very difficult in doing their routine every month and had to go to health services, where the role of a father who should seek and provide for his family members due to economic inadequacy was to seek loans from others, as well as the role of a mother who should only take care of the household, care for and educate the child he must help the husband in finding additional family income by selling mobile cakes.

Economic burden is also felt by the family for two reasons. The first reason is the decline in family income because most HIV / AIDS sufferers are in the productive age group and play a role as breadwinners in the family. The second reason is the amount of health costs that must be spent by the family for treatment / treatment of HIV / AIDS for a long time (Oluwagbemiga, 2007) Economic functions that play a role in fulfilling instrumental / facility support in meeting needs (due to the high cost of treatment and loss of family heads), the socialization function that plays a role in providing social network support in this case the support of sick family members in order to remain social activities (due to shame due to bad stigma that exists in the community consequently families are more likely to isolate patients), and health care functions that serve to provide support both direct assistance in daily care, access to health services, and information about things that PLWHA must do to maintain degree stability

In children with HIV / AIDS to carry out ARV therapy, it is necessary to prepare the family both socially, psychologically and financially for the child in providing medicine, therefore consideration needs to be given to the family, the health team and other social factors to make the decision to start ARV therapy. . So that obstacles or obstacles that will be faced during treatment can be handled with family. Parent or caregiver preparation is very important considering that ARV therapy is given for life, given every day and at the same hour, so as to get the maximum effect of ARV therapy, it takes more than 95% to emphasize viral replication and avoid drug resistance (Shah , 2007; ANECCA, 2011).

V. Conclusion

At the first theme where people in the case of parents have the most important relationship with financial conditions, accept that children whose consciousness must accept the risk of people's behavior, the attitude of a wise father to maintain household conditions, and measure mothers who faithfully caring for, educating and giving love to family accounts that can be used to solve the trials they face. Families in terms of caring for children with HIV / AIDS are certainly not feasible for their parents, with strong religious education. Love patterns for negative direction can be avoided. Belief in help from the Almighty Creator of Allah, which makes parents educate by approaching prayer, reciting and praying for self-healing and matter. The family in this case is the family's responsibility and needs for good home needs, food, food and tissues that are routinely carried out every month. Which does not require a little money, wherever the husband-someone else's work fulfills their daily needs, this is what encourages the mother to help the husband's role in helping her husband earn a living. Changes in the role of producing role friends at home will reduce the damage to children's attitudes and behavior to the child's level of approval of the treatment regimen. Open communication between family and children can result in a close and harmonious relationship, bad communication can be accessed by people who do not believe in children towards parents. In terms of the openness of status, children, it can be done everyday in the family in this study, they need other people in terms of the condition or status of the child. The stigma that exists in the community that forms a family of children, which can improve children's psychological well-being in the future.

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