

Conference Paper

Disclosure Process on Parents with Children with HIV: Qualitative Study

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Abstract

Background: The issue of the opening of the HIV status of children began to be considered essential for the health of children such as children is more enthusiastic about undergoing therapeutic treatment and this can reduce child mortality. In addition, disclosure of status to children can also help prevent transmission of HIV / AIDS to children's friends. Children become more careful in their behavior. for what??. *Disclosure* is a long process and requires the preparation of children, parents, health care workers. Positive impact by opening the HIV status of children since the opening of the HIV status helps children cope coping. **Objectives:** The aim of this study was to explore disclosure process on parents with HIV children. **Methods:** This research is a qualitative descriptive study using narration. Conducted in May 2019 in Bandung City NGOs, with 6 participants determined by inclusion criteria Parents who were diagnosed with HIV positive, Having children who were diagnosed HIV positive by snowball sampling sampling techniques. The method of data collection is 45 minutes of in-depth interviews and questions that focus on how parents reveal their child's status to their children. **Results:** The results of this study indicate that 5 out of 6 participants have revealed the status of children to children, 5 out of 6 parents have introduced the status of children from an early age indirectly by bringing to the clinic and community. and after the analysis process, four themes were found, namely the parents 'ignorance of the process of HIV transmission, the process of parental exposure to the child's illness, the response of the child's rejection to initial HIV treatment, and the parents' feelings after revealing the child's status. **Conclusion:** conclusions in the study indicate that most parents have revealed the status of children of children, most parents have introduced their child's status from an early age indirectly by bringing it to the clinic and the community.

Keywords: child, disclosure, hiv, parents

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1. Introduction

Worldwide in 2015 there were 36.7 million people living with HIV as many as 34.9 million adults. Covers, 17.8 million women and 1.8 million children aged less than 15 years. The number of new HIV infections in 2015 amounted to 2.1 million, comprising 1.9 million adults and 150,000 children aged less than 15 years. Number of AIDS deaths

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of 1.1 million consisting of 1.0 million adults and 110,000 children aged less than 15 years

(MoH RI, 2016) (Ministry of Health, 2017a), HIV / AIDS transmission from mother to child to date has already reached 2.6 percent of all HIV / AIDS cases reported in Indonesia. Number of HIV cases in children 0-4 years increased from 1.8% in 2010 to 2.6% in 2011 (DG & PL MoH RI, 2011). In the city itself the number of people living with HIV / AIDS by 2018 as many as 229 people living with HIV has decreased from 2017 as many as 329 people living with HIV. Meanwhile, according to age group the number of people living with HIV / AIDS in the city of Bandung in 2017 was 0 to 14 years as many as four children and 15 to 19 as many as five children. Meanwhile, in 2018 increased that children aged 0 to 14 years as many as eight children and 15 to 19 years as many as 4 children (Bandung City Health Office, 2018).

The issue of the opening of the HIV status of children began to be considered essential. Caregivers of children with HIV face a number of difficult decisions related to the child's HIV status fosterage, one of the difficult decisions faced by carers is when they should inform the child's HIV status fosterage (Vazquez, 2003). Several studies have found a positive impact by opening the HIV status of children since the opening of the HIV status helps children cope coping (Vazquez, 2003). One factor that makes caregivers of children with HIV opening the child's HIV status was that they felt that children have the right to know about *penyakitnya*, and to inform HIV status to a child can establish a trust relationship closer between caregivers with children (Aiges, 2008). While some families gave little information about HIV to their children generally feel that their children are too young to know about his illness, the family is worried about her son was not able to conceal their HIV status so that the potential rejection (discrimination) by others (Aiges, 2008). In Indonesia, children with HIV / AIDS have not been notified about the status of the disease if it is not considered an adult. Implementation Guidelines for HIV therapy in children issued by the Ministry of Health, explained that disclosure of HIV in children is recommended when nannies are in place and the child is considered mature (adult), and can keep a secret (Ministry of Health, 2014). Referring to the guidelines regarding the opening of the HIV status of the child issued by WHO (2011) stated that the opening of the status of children has been shown to have a positive impact on the health of children as children more enthusiasm undergoing treatment therapy and it can reduce child mortality. In addition, the opening status in children can also help prevent the spread of HIV / AIDS to their friends. Children become more cautious in behavior. Then your child can also better understand the condition of the body that are susceptible to other diseases that children become concerned about what is good for his health and what can make health deteriorated because children are able to recognize pain (World Health Organization, 2011). opening status in children

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2. Method

2.1. Types of research

The research is a qualitative descriptive study by narration. Data collection methods used in this study are in-depth interviews. This study was conducted in May 2019 in the NGO Bandung.

2.2. Population

The population in this study are the parents of HIV positive children who have HIV. researchers use Snowball Sampling technique Sampling. The inclusion criteria were used in this study on research that parents who are diagnosed HIV-positive, have children who are diagnosed HIV-positive, willing to participate in the study, physically fit and able to communicate well in an interview.

2.3. Instrument

The instrument used in this study interview guides. Guidelines for the interview were taken from a journal with four areas of major topics, namely (the child's HIV story) history of HIV in children, (HIV status disclosure) disclosure of HIV status to children, (factors Influencing disclosure) Factors affecting the disclosure, and (a means to Facilitate disclosure) how to facilitate disclosure.

2.4. Data Collection Procedures

Researchers have made a covering letter from STIKEP PPNI West Java, researchers have sought permission from the research that is of the body unity and political Bandung in Bandung as a place to do research and sampling carried out in the existing NGO in the city, then the researchers began to interview at the time of the interview, the researchers write interviews and record the sound recorder to remember all the information or data contained in the field, making it easier to do the analysis, after all the data collected later stage researchers to test the credibility, to perform a check. Once the interview is complete, researchers have compiled all the data that have been obtained from participants and researchers made the discussion, conclusions and suggestions.

2.5. Data analysis

Data analysis technique used in this research is the analysis of Colaizzi models, and for the validity of the results, researchers used *members check* to process the data obtained by researchers pengecekan to the participants. Objectives member check is to determine whether the data or information obtained and which will be used later in conformity with what dimaksud participants.

3. Results

Participants in this study had taken six people who met the inclusion criteria. And after the process of analysis obtained four themes, namely 1) the prevention of HIV, 2) HIV Education, 3) the child's response to treatment and 4) Parents calm after revealing the status of children.

4. Discussion

Parental ignorance of the process of HIV transmission Delays know the status also led to know the status of his late mother, and did not realize he was the source of transmission to their children. This transmission is based on a lack of knowledge and do not follow the program. Because if the mother knows from the outset, he mungin will make efforts to prevent the vertical transmission and can pursue the status of children born negative (Aebi, et al 2013). the transmission to the child, because there is no program PMTCT (prevention mother to child transmission of HIV), while PMTCT

is a package of interventions that require adherence by the mother in order to obtain results that effectively and efficiently to prevent transmission. The implementation of the PMTCT program in a big city is a program that focuses mainly in reducing cases of HIV / AIDS. Most women will have children one action, based on a lack of knowledge. In addition, transmission to infants caused during the phases of important and critical as during childbirth and lactation (Nguefack, et al. 2016).

The process of parental exposure to child illness According to Phillip Mandalazi (2014) that the child's age is an important factor when determining whether it is good or not to inform the child about his HIV infection, this study has recommended that a child who is living with HIV should be made aware of his or her status before the age of 10 years, The delay in informing children about their HIV status can have serious consequences. Adolescents living with HIV is expected to assume a sense of independence and personal responsibility, in the context of adherence to antiretroviral drugs. Delay in informing the children who are diagnosed with HIV will affect the bad habits of self-care and medication adherence.

Response of child rejection to initial HIV treatment According Hartati, (2005) that every individual has the curiosity and no one who has no curiosity at all, a child will look curiosity when he began to ask the things that he can see, hear, observe and so, If a child's curiosity is high then it will be more active in asking, child curiosity was then he would only ask about certain things that are interesting to him while the child curiosity low he would only ask when circumstances forced him to ask for it more silent or not so active.

Parents' feelings after revealing the child's status Parents are reluctant to reveal to the children about HIV illness suffered by children, because parents fear that children will face them with questions related to how the child is infected with HIV. Another reason parents are not able to disclose HIV status to children simply because they do not want the kids to worry, they argued that telling their children about their HIV status will trigger concerns that will eventually lead to the child becoming ill. Both parents are HIV-positive or guardians who are HIV-negative, indicating that they are reluctant to tell their children of their HIV status for fear the child will disclose her status to others and make others aware of HIV in their family (Mandalazi 2014).

5. Conclusion

Conclusions in the study indicate that most parents have revealed the status of children of children, most parents have introduced their child's status from an early age indirectly by bringing it to the clinic and the community.

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