

Phenomenology Study: Community Non Acceptance of Children with HIV/AIDS in Surakarta

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ABSTRACT

Background: There were 13 cases of children with HIV/AIDS in Surakarta in 2016. They were infected from their mothers. These children got stigma and discrimination from the community due to their HIV positive status. This study aimed to describe stigma and discrimination from the community to the children with HIV/AIDS.

Subjects and Method: This was a qualitative study with phenomenology approach. This study was conducted at Rumah Singgah Lentera (Halfway House of Lentera), Surakarta. The key informants for this study included managers of Rumah Singgah Lentera, fulltime secretary, children with HIV, and community members living in the neighborhood. The data were collected by in-depth interview, and then grouped into coding units and described and analyzed.

Results: The community surrounding Rumah Singgah Lentera, Surakarta, viewed children with HIV/AIDS as a disgrace. Various kinds of discrimination such as non-acceptance, alienation, restriction have been addressed by the community to the children with HIV/AIDS. The community has also stigmatized managers of Rumah Singgah Lentera, Surakarta, that they were also HIV infected and made profit of HIV/AIDS donation they received. This stigma occurred because of lacking in HIV/AIDS knowledge, particularly its mode of transmission. Stigma and discrimination have caused psychological disorder among children with HIV/AIDS. They often feel sad, alienated, and cry, so that they often withdraw from their social environment. In term, they feel despair and decline to take ARV drugs.

Conclusion: there is a need to enhance knowledge in HIV/AIDS, its mode of transmission, method of prevention, and its treatment for the community, in order to repress stigma and discrimination from the community.

Keywords: HIV/AIDS, children, stigma, discrimination.

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BACKGROUND

Increased cases of HIV / AIDS are still a complicated issue for all countries in various parts of the world. In fact, there is a new group of people with HIV / AIDS, namely children. World statistics in 2015 mentioned 1.8 million children under 15 years of age living with HIV / AIDS (UNIADS, 2016). In Indonesia, there are at least 898 children with HIV / AIDS in the age range of 4-15 years. This data was obtained from DG PP and PL on the Spiritia Foundation website

June 5th, 2016. Central Java ranks 5th in Indonesia for the highest number of HIV / AIDS sufferers based on data from KPA, and Surakarta City ranked second after Semarang City with the highest HIV / AIDS rate in Central Java. There were 28 cases of HIV infection and 48 cases of AIDS positive in Surakarta City in 2016. There were also 13 cases of children with HIV positive and 11 of them lived and cared at the Halfway House of Lentera, Surakarta (KPA Surakarta City, 2015).

The challenge of HIV/AIDS prevention is not only to prevent the spread of infection but also its treatment. The new problems arise become more complex, namely stigma and discrimination on people with HIV/AIDS (Shaluhayah et al., 2015). Stigma of Children with HIV/AIDS is often linked to deviant behavior that causes HIV / AIDS infection, but unlikely ADHA, transmission of HIV/AIDS in children is more caused by maternal infection from mother to child (Becquet et al., 2012; Shen et al., 2015). However, Children with HIV/AIDS still get stigma and discrimination by the community.

SUBJECTS AND METHOD

1. Study Design

This was a qualitative study with phenomenology approach. The study seeks to explore information about the Children with HIV/AIDS experienced stigma and discrimination surrounding by communities. This study was conducted at Rumah Singgah Lentera (Halfway House of Lentera), Surakarta. This location was chosen because Halfway House of Lentera, Surakarta treats children with HIV/AIDS from various regions, both from within Solo City and from outside Solo City (KPA Surakarta City, 2016).

2. Population and Sampling

The study subject was taken by purposive sampling technique according to the criteria. The key informant of this study is the manager and caregiver at the Halfway House of Lentera, Surakarta. The main informants in this study were Children with HIV/AIDS and auxiliary informants consisting of residents who lived around the Halfway House of Lentera, Surakarta.

3. Study Instruments

The data were collected by in-depth interview with the informants. Data collection tools used were interview guides, voice recording devices, notebooks and cameras to document the data.

4. Data Analysis

The data that has been obtained will be analyzed using systematic coding methods (Creswell, 2013). A collection of significant statements grouped into information units (Coding), described and interpreted. This study aimed to explore the stigma and discrimination of the community against Children with HIV/AIDS in the neighborhood.

RESULTS

Child survival is a child's right that must be protected by the country, government, community, family and parents, including children with HIV / AIDS (Republic of Indonesia Law No. 23 Article 2 of 2002 concerning child protection). Children with HIV/AIDS who lived in Halfway House of Lentera, Surakarta still had to experience rejection as a result of community stigma and discrimination. They moved from one place to another because they were rejected and expelled by the surrounding community. Children with HIV/AIDS currently lived in Tegalrejo Village, Sondakan, Laweyan, Surakarta. The community strongly refused the halfway house for children with HIV/AIDS in their neighborhood. They wanted the house contracted by Halfway House of Lentera, Surakarta to be immediately emptied and not be in the neighborhood anymore.

"Menolak mbak, kabeh ki tetap menolak. Nek mboten percoyo sak sak e wong, sak sak e wong jenengan takok i tengmriku, pun sak kecekele wong sampan tekoki. Kan seng beban yo aku..... wong dekingi sakjane yo arep didemo, neng aku sek gak oleh sek..... yoo kan mengganggu, wong warga kulo menolak og mbak yo kulo yo moh." (Citizen Informant 1)

Meaning: "Refusing, Miss. All people still refuse. If you don't believe it, you can ask everyone you meet here. I feel burdened. Actually yesterday the community will do a demo but I don't allow it first. Very disturb-

ing, because my residents also refused, I would still refuse.”

1. Stigma and Discrimination of Society

The attitude of the community's rejection of children with HIV/AIDS in their environment was inseparable from the community's stigma about the HIV/AIDS disease suffered by children with HIV/AIDS. The surrounding community considered HIV/AIDS to be very dangerous and easily transmitted. This made a feeling of excessive fear to interact with children with HIV/AIDS.

“Wedi mbak.. malah bojo kulo luweh wedi. Moh... malah ngejak pindah pulang ke rumah orang tuanya..... ya namanya orang awam kan yo takut tertular mbak, pokoknya saya taunya ya penyakit berbahaya belum ada obatnya tur menular.” (Citizen Informant 2)

Meaning: "Scared. My wife was even more afraid. She did not want to, instead invited me to go back home to her parents' house. As a layman, we must be afraid of contracting, Miss. I just know that this dangerous disease has no cure and is also contagious."

The community's stigma was also shown by indifference and antipathy. They wanted children with HIV/AIDS not to live in the neighborhood anymore.

“I'm worried if they play with children, Miss. Actually kids don't know, but as parents, I'm afraid. I can't keep watching, so I can only worry. They should look for another place and not here. It's a dense environment, lots of kids.” (Citizen Informant 3)

Negative assumptions towards children with HIV/AIDS directly or indirectly resulted in the surrounding community grouping children with HIV/AIDS as a minority group in the community. children with HIV/AIDS and Halfway house of Lentera, Surakarta management had never been involved in any activities in the village.

“They did not participate in the village activity. They cannot participate. They were not included in the competitions on Independence Day.” (Citizen Informants 1)

In addition to limiting the children with HIV/AIDS socialization, the community is also indifferent and isolated. This was felt by one of the children with HIV/AIDS at the halfway house of Lentera, Surakarta.

“You can't play there (neighbor next to the Halfway House of Lentera). If you go there, you are told to go home. There, go in there, as they say.” (Children with HIV/AIDS informant 1)

Parents also forbade their children from playing with children with HIV/AIDS, as follows:

“No ... I never knew the situation there. I never saw it too. Why should I go there? I am afraid. My children can't go there. If there are those who come to play here, I also don't allow it. My children cannot play with them.” (Citizen Informant 3)

2. Causes of Stigma and Discrimination in the Community

The lack of community knowledge about HIV/AIDS caused people to have a wrong perception about HIV/AIDS transmission, so that people were too scared and tend to limit all forms of interaction with children with HIV/AIDS. People assumed that HIV/AIDS could be infected if they were close to children with HIV/AIDS. It was not uncommon for people to expel children with HIV/AIDS when they came to their homes. The surrounding community also considered that the HIV virus could be contagious like ordinary influenza virus or contagious from sweat attached to the items used by children with HIV/AIDS.

“Saikimu lak kringet neng nggon kursi, ta tekokne dokter spesialis nek kringet piye ngono yo raiso jawab lo mbak, kan yo angel.” (Citizen Informant 1)

Meaning: Now about the sweat sticking to the chair. I asked a medical specialist about whether sweat tapping on this chair would be contagious, he also could not answer. It made it difficult!

"Kan yo gak tau mbak yaa, jaga-jaga aja. Namanya virus ya nular lo mbak. Wong bocah nek enek wong gedi pilek ora nyedak ae yo ketularan kok."

Meaning: We do not know, just in case. However, this is a virus. Children can get infected if there is an adult who is having the flu, even though the child is not approaching.

3. Psychological Impact On the Children with HIV/AIDS

The stigma and discrimination experienced by children with HIV/AIDS had psychological impact on them. Although children with HIV/AIDS did not really understand the stigma and discrimination committed by the community, but the unfair attitude and isolation carried out by the community often made children with HIV/AIDS felt disappointed and sad. They were often depressed, crying, insecure and sometimes sad, why the surrounding community was away from them, without knowing the cause of them being shunned. In fact, it was because of the illness they experienced. The psychological stress of the child also arised as a result of the illness they experienced, felt hopeless and was often shown by not wanting to take medicine.

"I do not know. They (neighbors in their neighborhood) look dislike. They whispered to others. I don't know, maybe because of this disease. Sad if I think so. I ever cried. I'm crying in Mrs. Rina's room." (Children with HIV/AIDS informant 1)

"No, I don't want to go home, I don't have friends there. You know, they don't want to be afraid of infection. Yes, I had ever skipped my medicine, just because I

was lazy to take it. I can't recover anyway." (Children with HIV/AIDS informant 2)

"Poor children. They sometimes do not understand that he was excommunicated. Once 'MJ' complained. He said, 'Why if I play with them, the mother did not allow it. They were all told to come inside, so I was alone.'" (Caregiver at the Halfway House of Lentera, Surakarta Key Informant)

"Here, the one who has the worst psychology is P. The last time he got the news that his grandfather died, his HB immediately dropped again. He had to be hospitalized at that time. The doctor said the medicine wasn't working because his psychology was bad, so the medicine was immune to his body." (Manager at the Halfway House of Lentera, Surakarta Key Informant)

DISCUSSION

Based on Labeling Theory by Edwin M. Lemert and George Herbert Mead in Sunarto (2004), the stigma and discrimination of the surrounding community arose due to the tendency to place children with HIV/AIDS in a minority position because of having HIV / AIDS. This put children with HIV/AIDS in the "Primary Devian" in the labeling theory. Primary Devian became the object of labeling the community, in this case, stigma and discrimination. Stigma and discrimination were more structured and systematic. The findings in this study stated that children with HIV/AIDS were considered as children who had to be shunned because they were dangerous. They could transmit viruses and diseases to the people around their homes. The community limited all forms of direct interaction with children with HIV/AIDS, such as prohibiting their children from playing with children with HIV/AIDS, even reluctantly using chairs and anything that children with HIV/AIDS had ever imposed. The community also did not involve children with HIV/AIDS in acti-

vities in the village. Then, structurally, from the villagers to the village apparatus, they tried to keep children with HIV/AIDS from living in the neighborhood again.

The stigma and discrimination of the surrounding community to children with HIV/AIDS at Halfway House of Lentera, Surakarta in this study was in accordance with previous study by Shaluhiah et al.(2015) in Indonesia and Yi et al.(2015) in Cambodia that people with HIV/AIDS, no exception children with HIV/AIDS, were still getting very strong stigma and discrimination in the community. Although children with HIV/AIDS did not show symptoms of illness, the community still considered they were dangerous and had to be shunned, and they became a matter of gossip.

Labeling from the surrounding community through stigma and discrimination left a psychological impact on ADHA called Secondary Devian. ADHA tended to act like the people labeled, that they were children with deadly diseases and endangering others. ADHA felt inferior so that they withdraws from their social environment. In addition, the psychological impact that ADHA felt was a feeling of sadness and distress that was shown through a mood of sadness, crying, feeling ostracized, feeling hopeless and not taking medicine. The psychological impact experienced by children with HIV/AIDS often resulted in physical reactions, children became sick more often.

The findings on the impact of stigma and discrimination on children with HIV/AIDS psychology supported the results of previous studies by Handajani et al.(2012) and Rzeszutec et al.(2016) that one of the most important aspects in the treatment and care of patients with HIV/AIDS was to establish an adequate psychological state. The views, beliefs, mental health and social support that were formed would greatly influence the patient's acceptance of the

disease and its adherence to the therapy given.

There needs to be a model of efforts to eliminate stigma and discrimination in children with HIV/AIDS that are formed and implemented through cross-sector cooperation. Thus, the stigma and discrimination at children with HIV/AIDS can be minimized by the occurrence and the children's rights are protected.

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