

# HEALTH STATUS AND PSYCHOLOGICAL WELL-BEING OF CHILDREN INFECTED AND AFFECTED WITH HIV IN CENTRAL JAVA INDONESIA

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## ABSTRACT:

**Background:** Besides facing an increased risk of death, children with HIV infected and affected also confront to stigmatization, discrimination, rejection and lack of love and care. HIV affected means children without HIV but one or both parents HIV positive. This study aims to describe the health status and psychological well-being of children with HIV-infected and affected and explore the caring behavior.

**Methods:** This was a qualitative study that employed both structured and unstructured questionnaire was performed to 47 caregivers whose children were infected and affected by HIV. In addition, in-depth interviews were used to 5 case managers, 3 health personals and 4 caregivers whose children have experienced with opportunistic infection and 2 caregivers whose children were orphaned due to HIV parents' death, to explore the problems of their care arrangement and treatments as well as handling stigma and discrimination from the community.

**Results:** There were ten HIV infected children and eight of them had received antiretroviral therapy. Health status and psychosocial well-being of children with HIV infected were much worse than those affected. Some of them suffered from diarrhea, tuberculosis or skin disease as well as psychological symptoms such as often feeling head-ache, overly dependent to caregiver, poor appetite, bedwetting, short temper and even depression primarily in older children. There was no differences in the care pattern between HIV-infected and affected. Most of them raised by their biological mother or extended family member when parents died or absent. Caregiver characteristics such as knowledge and attitude about caring and socio-economic status, stigma and discrimination from community were related to the caring behavior and contributed to children health status and psychosocial well-being.

**Conclusion:** Caregiver caring behavior has great impact on children's health status and psychological well-being primarily for children with HIV infected and affected. In terms of caring, HIV infected children were provided more attention for routine medication since they face many problems related to their immune system. In addition, fear of stigma and discrimination makes parents or caregivers hide the children's HIV status, thus affecting the care and treatment that the children receive.

**Keywords:** Children, Health status, HIV infected, HIV affected, Psychosocial well-being

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## INTRODUCTION

Since first reported in 1987, the Human Immunodeficiency Virus (HIV) epidemic in Indonesia is one of the fastest growths in Asia. In 2016, an estimated 812,798 people are infected with

HIV. The cumulative number of people living with HIV has increased significantly from the initial

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2,682 cases in 2004 to 167,350 on March, 2015. Likewise, Acquired Immunodeficiency Syndrome (AIDS) cases has also increased significantly from 3,692 in 2006 to 66,835 on March, 2015 [1, 2].

Central Java province was ranked second among 10 provinces for new cases in 2014, and ranked 6th of higher cumulative cases in Indonesia. Risky sexual practices and drug use was found to be the highest risk factors for HIV and AIDS transmission [2]. Integrated HIV and Behavior Survey reported, HIV was found among 52.4 percent of injecting drug users, 10.4 percent among female sex workers (FSW), 4.6 percent of indirect sex workers and 0.8 percent of Female Sex Worker's (FSW's) clients [2, 3].

The discovery of HIV cases among FSW's clients is an indicator that the infection has entered the general population since most FSW customers are married men. An estimated 10 million men in Indonesia buy sex from FSWs each year [4]. Ministry of health (MOH) on March, 2015 reported, 58.2 percent of the total HIV cases occurred in men and 41.8 percent in women. These data clearly illustrates that the proportion of HIV cases in women is experiencing a significant increase in the last 8 years, exceeding the initial estimation [1, 2, 5].

HIV transmission from an infected mother to her children is likely to increase along with the increasing number of HIV-positive women who were infected from their partner or as a result of their risky sexual behavior. HIV prevalence among pregnant women is projected to increase from 0.38 percent in 2012 to 0.49 percent in 2016, and the number of HIV- positive pregnant women who require Preventing Mother to Child Transmission (PMTCT) services is expected to increase from 13,189 people in 2012 to 16,191 in 2016 [6]. Likewise, the number of children under 15 years who contracted HIV from their mothers at birth or during breastfeeding has been increasing from 4,361 in 2012 to 5,565 in 2016, which means there will be an increase of child deaths due to AIDS [6].

PMTCT has proven to be a very effective intervention for preventing HIV transmission from mother to children that covers a wide spectrum, not only to housewives, but also to female sex workers, female injecting drug users, migrant workers and etc, which also pays attention to human rights and provides gender-sensitive services. In developed countries, the risk of a child contracting HIV from the mother can be reduced to less than 2 percent due to the availability of PMTCT intervention with

optimal service. However, in developing or poor countries, due to the lack of access to interventions, the risk of transmission remains between 20 to 50 percent [6].

In the third decade of the HIV/AIDS epidemic, when people are still affected by the speed of the disease, children are the most burdened. With the increasing number of parents who is infected with HIV, the number of children infected and affected by HIV is also likely to increase [6]. Along with the increase in the HIV and AIDS pandemic, impact on children, families and communities are also increasingly widespread. Starting when parents are infected with HIV, then entering the stage of AIDS and death, children face a far greater risk than just losing their parents. When parents die of AIDS, the children are three times more likely to experience a period of crisis, even though their status is negative [7-11].

Children with HIV infected and affected face a variety of risks associated with health, social, economic and welfare [11]. Firstly, children with HIV face a higher risk of death from the disease from their mothers [12, 13]. The children are usually detected and diagnosed when they are got opportunistic infection and so many of them eventually dies without ever receiving treatment [14]. Secondly, parents with HIV infection makes children more likely to experience problems in development and quality of life [15, 16]. Children who are affected by HIV tend to be more vulnerable to malnutrition, physical and mental development issues. Research has shown that children affected by HIV tend to have lower level of intelligence than non-HIV affected children [17, 18].

Once parent(s) is infected by HIV, the socio-economic conditions of the family will be dropped because of the infection will be lessening the ability of parents to meet the nutritional and health needs of children. In the surviving parents, the child may not be able to get adequate care and support due to the inability of parents to work optimally. In some extreme cases, children become caregiver of parents, being forced to drop out of school and make a living for the parents who are infected with HIV [9, 19, 20].

When parents die, children become orphans and the parental responsibility is then handed to the immediate family. The need for nutrition, health and education are not necessarily guaranteed since not all children are taken care of by financially capable families. Moreover, stigma is still common from the

surrounding environments, including health services, making children feel isolated and then rejecting the services they deserve [10, 16, 21]. Children affected by HIV are also vulnerable for exploitation and trafficking. The rejection they receive from surroundings forces them to live on the street which actually increases the likelihood of them contracting HIV [7, 22].

HIV does bring a very broad impact on the life of a child, whether infected or affected. Once a family member is diagnosed with HIV, their life will change dramatically, in terms of financial, health and social services. Since they are the most vulnerable group in the community due to have inability to survive on their own without adults help, children are the ones who will feel the harshest impact of the parents' HIV infection. Whether infected or not, children who live with parents who are infected with HIV will also suffer from some forms of crisis. Therefore, this study aims to describe children health status and psychosocial well-being who have HIV/AIDS parents and analyze the caring pattern of children with HIV infected and affected.

## METHODS

### Participant and study site

This is a qualitative study that uses both structured and unstructured interviewing, supported by descriptive statistics to summarize some features of the respondents. Purposive sampling technique was employed to select caregivers who take care of HIV infected or affected children with age ranged one to 12 years old. They were contacted through their case managers or counselors who have an access to them. Temanggung, Semarang, and Grobogan Districts were selected because of the highest cases of HIV/AIDS among other districts in Central Java. There are 47 caregivers who were participated to interview by using structured questionnaire. In-depth interviews using unstructured questionnaire were conducted to 5 case managers and 3 health personals including 4 caregivers/parents whose children have experienced with opportunistic infection and 2 caregivers whose children were orphaned due to parents' death. All interviews with caregivers were conducted in the caregivers' home along with the children. Whilst in-depth interview with case managers and health personals were conducted at peer support routine meeting in the hospital. Caregivers whose children have opportunistic infection and been hospitalized were excluded from

the sample.

### Data collection and analysis

The characteristics of caregivers and children, parenting behaviors, including knowledge, attitudes and stigma of caregivers, and children's health and psychological status were collected through structured questionnaire. In-depth interviews were employed to explore case managers' and health providers' opinions in terms of family care, supports and treatment for antiretroviral (ARV) medication especially for infected children and history of infected parents. In addition, in-depth interview to caregivers were conducted to describe and explore their experiences in caring, supporting and monitoring their children health as well as psychological well-being. Children's health status and psychological well-being were measured by using last six months caregivers recall in terms of their children experiences in opportunistic infection, and verified through children medical records as well and how often psychological symptoms happened to their children such as stomach ache, headache, sleeping difficulty, poor appetite, fear, depression, bedwetting, short temper, nightmare and overly dependent to caregiver. Descriptive analysis including percentages, mean, median and standard deviation were employed to identify demographic data and study variables. Chi-Square test was also employed to analyze correlation between caregivers' demographic characteristics and children health status. Qualitative data from in-depth interviews with case managers and health personals including caregivers were analyzed using thematic content analysis which consisted of multiple readings of transcribed interviews to establish code based on the data. The codes were subsequently categorized into themes. The themes of open ended questionnaire composed of information on caregiver experiences on caring their children including the main barriers which come from their situation and condition, their children themselves, health services as well as community.

### Ethical consideration

This study has been approved by Institutional review board at Faculty of Public Health Diponegoro University, Semarang Central Java Indonesia (no. Ref: 165/EC/FKM/2012 at 3<sup>rd</sup> December, 2012).

## RESULTS

Table 1 shows that more than half (61.7%) of

**Table 1** Characteristics of caregiver

Variables	n	%
<b>Caregiver age (years)</b>		
<20	2	4.3
20-29	11	23.4
30-39	24	51.0
≥ 40	10	21.3
Total	47	100.0
<b>Gender</b>		
Female	34	72.3
Male	13	27.7
Total	47	100.0
<b>Caregiver education</b>		
Never go to school	1	2.1
Primary school	23	48.9
Junior high school	16	34.0
Senior high school and up	7	15.0
Total	47	100.0
<b>Caregiver occupation</b>		
Farmer	2	4.3
Labor	9	19.0
Private business	12	25.6
Teacher	2	4.3
Housewife	15	31.9
Others	7	14.9
Total	47	100.0
<b>Income (million rupiah)</b>		
< 1	26	55.3
1 - <2	20	42.6
≥ 2	1	2.1
Total	47	100.0
<b>Relationship with children</b>		
Mother	29	61.7
Father	9	19.2
Extended family members/relatives	8	17.0
Social worker	1	2.1
Total	47	100.0

children were brought up or have experienced up bringing from their biological mother. After the death of the biological mother or father, their extended family member such as aunt, uncle, grandmother/grandfather took over the responsibility to looking after the children (38.3%). Whilst formal education of caregivers were mostly primary and junior high school (48.9% and 34%), most of them admitted, obtained enough information about HIV and AIDS. Case manager or supervisor is mentioned by most caregivers has been providing the most relevant information, followed by health providers, and the mass media. One third of caregivers (31%) were housewife, followed by private business and labor (12% and 9% respectively).

Most caregivers which were parents of the children have been undergoing HIV treatment.

Risky sexual practices among heterosexual become the major cause of the infection. The vast majority of mothers contracted HIV from their husbands who buy sex from prostitute.

None of the mothers of children with HIV infected or affected participated in the PMTCT program on their last pregnancy. Because of their unknown HIV status, they didn't get ARV prophylaxis during pregnancy and they gave birth at midwives' private practice or hospitals with vaginal delivery. Most mothers know their status only after knowing their child HIV positive. Stigma and discrimination against people with HIV in Central Java caused many people living with HIV/AIDS (PLWHA) hide their status or being afraid to take the test. This study revealed that if the family member infected they have to hide their HIV status

because of fear to reject from surrounding communities, including workplace and school. Some parents disclose theirs and their children's status only to their immediate family.

In-depth interview results showed that most caregivers keep their children's status secretly, including to the children themselves because they were still too little to understand about this disease. However, children who already get into adolescents know that they suffered for the same disease as their mother's.

*"I think he does know. The point is he knows, its just that he's not sure whether or not he wants to disclose it. He knows he has the same illness as his mother since he was always ill from grade 1 until 2 PS. Then I decided to give him ARV, cos before we gave him ARV, he would catch a fever every once a week. I couldn't stand watching him suffer so I went to consult to the doctor. After taking ARV, he's been healthy till now..." (Y case manager)*

In general, the majority of caregivers (68.1 %) have inadequate knowledge of HIV. Only 76% of caregivers perceived that mosquitoes could not transmit HIV, and 74.5 % of them know that HIV can be transmitted from a mother to child. In terms of the HIV symptoms, only a few of them were able to identify early symptoms such as presence of swollen glands in the neck or groin (23.4%), sweating at night (29.8%), shortened breathing (6.4%) and easy bruising (10.6%). Nevertheless, the majority of caregivers (72.3 %) acknowledged that heavy and prolonged diarrhea is the main symptoms of HIV infection. This is because of their experiences with these symptoms that often happen on their children.

For them who are not biological parents, taking care for children with HIV did not seem to be perceived as a burden. About 55.3% of families and caregivers have low socio-economic conditions (income less than 1 million rupiah per month) (Table 1) and knowledge of HIV become the main factor influencing the pattern of care. Caregivers acknowledged that children infected with HIV often experience pain and need to consume of ARV drug every day, so that required more intensive attention from the family, either moral or financial supports. Although most of the caregivers (61%) were already actively looking for information about child development, nevertheless, caregivers' knowledge

and behavior regarding pattern of care is still relatively inadequate, as reflected in the results of in-depth interview excerpt below:

*"I had a little trouble taking care of him for the first time. He doesn't know what kind of illness he's suffering from, what it is HIV. At first I did not know the symptoms of HIV either. I didn't know where to get the drug, the only thing I want was for my son to recover. They recommended ARV therapy, so yes I followed what they said so that I can be healthy and my son also can be healthy .." (Mrs. Y mother with HIV )*

Most of the caregivers expressed to have no fear of touching the saliva, sweat, and feces of PLWHA. They were also not afraid to bath or touch an infected person's body and sleep with people living with HIV. However, negative perspective reflecting stigma shown by many of caregivers who believe that PLWHA is as a punishment for their bad behavior. The presence of HIV stigma from a caregiver, will certainly affect the pattern of care which will eventually affect the health and psychological condition of the infected child. Whilst the majority of caregiver had in adequate knowledge, more than half of them showed a positive support in taking care of children with HIV. They agreed that an infected child should be given more attention and love than a child who is only affected by HIV.

To protect children from opportunistic infections, caregivers control child's diet and limit the time playing outdoors. Although caregivers did not provide specific vitamins to maintain their children's condition, they paid attention to the children's food intake and provide ARVs regularly. It seems there was no difference in patterns of food consumption and provision for children, both infected and affected by HIV. It should be noted that HIV infected and affected family were usually among low or middle income ones. Therefore, providing a special menu becomes almost impossible. Children tend to be accustomed to eating foods that are available at home, regardless of their specific needs.

*"No, this kid eats just about anything, the same as the adults. Sometimes thiwul, corn rice etc. They also like vegetables. Sometimes cassava leaves, anything basically. As long as it is provided at home, because I don't come from a rich family" (in-depth interview with caregiver Mrs. W)*

**Table 2** Children's health status

History of illness	Child's status			
	Infected (n=10)		Affected (n=37)	
	f	%	f	%
Fever in the last 6 months	0	0	0	0
Chronic diarrhea in the last 6 months	1	10.0	1	2.7
Pneumonia in the last 6 months	1	10.0	0	0
TB in the last 6 months	2	20.0	0	0
Hepatitis in the last 6 months	0	0	0	0
Herpes in the last 6 months	0	0	0	0

**Table 3** Psychosocial conditions of children

Reported symptoms	Frequency (n=47)	Percentage (%)
Reported headache	5	19.2
Reported stomach ache	16	44.0
Prolonged crying	7	14.9
Depression	7	14.9
Short temper	11	23.4
Fear	9	19.1
Aggressiveness	1	2.1
Talk about death	9	19.1
Nightmare	9	19.1
Sleep difficulty	9	19.1
Bedwetting	11	23.4
Poor appetite	14	29.8
Overly dependent to caregiver	19	41.4
Seclusion	4	8.5
Refuse to go to school	1	2.1
Involved in fights	3	6.4
Delinquency	1	2.1

The vast majority of children infected and affected with HIV has aged between 2-5 years old, and relatively balance between sexes. Of 47 children, 76.6% have had HIV test and 10 of them (21.3%) were reactive.

Table 2 shows the health status of children HIV infected and affected. It shows that upper respiratory tract infections, tuberculosis, and chronic diarrhea are most common reported health disorders (10%, 20% and 10% respectively) in the HIV infected children. Whereas the affected children, although most of them has suboptimal health due to lack of nutritious food intake, but they were not reported to have a chronic disease. Only 1 child (2.7 %) showed AIDS-like symptoms such as reduced intellectual ability, chronic diarrhea and skin irritation. Of 10 children pronounced HIV reactive, 8 of them have been consuming ARVs obtained from the hospital.

In terms of psychological conditions, the study revealed that 44 % children reported stomach-ache and 41.4 % overly dependent to caregivers primarily

to the younger one. A quarter of the children also experience with the symptoms of poor appetite (29.8%), bedwetting (23.4%) and short temper (23.4%). The symptoms of fear, talk about death, nightmares and sleep difficulty were also happened primarily to the children with HIV infected. Among the older ones, disturbances are seen in short temper, complaining of abdominal pain, prolonged crying and depression (14.9 %). In general, the majority of children (53.2%) suffered from minor psychological disorders (experiences with less than 2 symptoms), 8.5% suffered mild psychosocial disorder (experiences 2-3 symptoms) and 2.1 % had severe psychosocial disorders (more than 3 symptoms), Table 3.

Results from in-depth interview with case managers and caregivers showed that stigmatization and discrimination often cause children to isolate themselves or withdraw from the community. Especially when a child enters the school age, stigmatization becomes the most severe threat.

Many of the children infected and affected by HIV were shunned or even expelled from school because there are no laws protecting them. The psychological pressure becomes more severe when the child is able to understand the meaning of social isolation received from their surrounding such as described by the following informants.

*"We didn't get any from the family, but from the community. He told me himself: Mum, he's not allowed to play with me anymore. They say I have a disease..." (In-depth interview with Mrs. Y a caregiver)*

On the contrary, caregivers think that children with HIV should be given the opportunity to mingle with other children. By placing them in public schools, caregivers expect children to be able to grow like other children of his age and will further help strengthen the children with HIV in terms of psychological development.

Chi-square test shows only caregivers' attitude to the caring behavior related to children health status, but not any independent variables showed significantly related to children's psychosocial condition. Children who were cared for at home by their immediate family have better psychological status compared to children who were cared in foster homes or other shelters. This is possible because the majority of children are under the age of 5 years and most of them still under the care of their mother.

## DISCUSSION

As predicted, this study shows that the health status of HIV infected children was much worse than the affected one. HIV infected children face many problems as the complexity of their illness and treatment as well as concerning levels of treatment failure, drug side effect and resistance including higher comorbidity such as diarrhea, pneumonia, TB and mortality compare to their affected [23]. Chronic illness such as HIV need long term treatment which is closely linked with the issue of medication adherence. Adherence to medication is the critical behavior in HIV treatment especially for the children [23]. Some studies revealed that adherence to medication could be improved by disclosing HIV diagnosis to the children. Sometimes some of the children get tired or bored of taking daily medication. If they are given adequate information about their illness they would play an active part of medication such as reminding

caregiver of side effect, timing take medication and timing to medical control [24, 25].

The chronic illness conditions primarily HIV/AIDS in children pose a range potential psychosocial challenges not only to the child but also to the family members and health care providers [26]. Such as parent delay disclosing the children as well as their own HIV due to stigma and possible social consequences, lack of knowledge and awareness of caregivers, heavy workloads of case managers and health providers [25, 27].

In terms of psychosocial well-being, this study shows that children with HIV infected often suffered more than three psychological disorders such as overly dependent to caregivers, poor appetite, short temper, bedwetting, feeling head-ache. Some survey reported that children with chronic illness in general are found at greater risk for psychiatric problems including depression, anxiety and feeling of isolation [23, 26].

Many factors contributed to children health status and psychological well-being with HIV infected and affected. The most important factor is caregiver characteristics, caregiver-child relationship and capacities in caring and supporting them to dealing with physical and emotional disturbances. HIV infected and affected children need love, security and sense of well-being and belongingness. Children characteristics such as age, and material poverty also contributed to the children health status and psychosocial well-being [24, 28].

Most of caregivers in this study were come from low and middle class families. Since most of them only obtained low education and having low socio-economic level, taking care of children with HIV is clearly problem of its own, since naturally a child HIV infected or affected needs more adequate health protection, nutrition, health services and education in order to support their growth and psychosocial development [18, 19, 29]. Other study showed that living below poverty level was significantly associated with children psychosocial status. In addition, caregiver characteristics including child-caregiver relationship, most notably related to communication with caregiver about problems also correlated to children depression primarily with older children or adolescent [24].

In terms of health protection, the majority of caregivers (53.2%), care the children with HIV at their own home, together with other family members. Caregivers stated that the best place for children is with their guardian family, in their own

homes, not in shelters, orphanages or other special homes. Most caregivers of infected children provides frequent medical checks up compared to caregivers of affected children. This is reasonable because infected children have higher possibility or risk of health issues due to their immune system, thus, referral-seeking behavior to a more complete health service (hospitals) are also shown more by the caregiver of infected children compared to affected children [26]. Therapeutic support has the greatest role in the care of children with HIV infection because they are most vulnerable to health problems [25, 26, 28].

Only caregiver attitudes have influence on the child's health status. This is not compliant with existing studies that showed very significant correlation between children's health and quality of care. A child's relationship with parents also has an impact on their ability to survive. Children who are in the care of the elderly (grandmother, grandfather) also typically have poorer health status than children who are in the care of their own parents since most elderly caregivers have less information in terms of nutrition provision and health care in general including on HIV and AIDS [7, 18, 30]. Other studies also show that children who are in the care of adults with chronic illnesses tend to consume less food than children who are in the care of healthy adults [18, 22, 31].

In developing countries such as Indonesia, the family having children with HIV is generally a family dealing with crisis, illness, lack of resources and social isolation. The need of food and shelter may seem to be much more important than the need of counseling [32, 33]. In fact, psychological stress due to illness and death of parent as well as poverty condition is actually the heaviest burden experienced by children in addition to stigmatization, discrimination and social isolation [12, 33, 34].

## CONCLUSION AND RECOMMENDATION

Children with HIV infected were much more suffered and vulnerable in health and psychosocial problems compare to the affected one. Four of ten HIV infected children in this study have experienced some opportunistic infections probably due to non-adherence to medication in long term ART treatment which related to decreasing of their immune systems. HIV infected children also facing more psychosocial problems than the affected one such as overly dependent to caregiver, short temper, poor

appetite and reported head-ache. The caregiver characteristics and health, caregiver-child relationship and living in poverty provides a broad impact on children health and psychosocial condition. Although children's health status in general is relatively well despite having experienced opportunistic infections, psychosocial impact of HIV to children and families were more obvious, shown by the stigma and discrimination experienced by children HIV infected or affected.

In term of the caring behavior, there is no difference pattern of care between infected and affected children. Only infected children were given more attention regarding routine medication and food intake. Health check-ups were provided more frequently on infected children than affected one. Inadequate knowledge about HIV and fears of stigma from family and society causes caregivers or parents, especially mothers to hide their as well as their children's HIV status.

This study suggests that the need programs to reduce the stigma of HIV in the community, which can be supported by community leaders intensively by providing comprehensive information regarding HIV transmission, so that incorrect myths will not occur in the community. PMTCT program is important to be provided for pregnant women at risk of HIV, this can be improved through screening during ANC by midwives so that mothers can be recommended to take test and participate in the PMTCT. Social impact due to HIV in children should be concerned to all parties through mitigation programs for infected and affected children due to their HIV+ parents.

This study has several limitations. Firstly, our study were the small size of the study population, due to only covered 3 districts in Central Java. Secondly, health status and psychosocial well-being of the children which measured by caregivers recall at last 6 months with proved by children medical record, could be potential bias, since the medical record of the children was not complete and the data only collected based on caregiver memory. Secondly, not all caregivers were in-depth interviewed to explore their experiences in caring, supporting and treating their children HIV infected or affected.

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