



# Prevalence and factors associated with human immunodeficiency virus disclosure status in children at Sanglah Hospital Denpasar

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## ABSTRAK

Manajemen yang komprehensif terhadap infeksi *human immunodeficiency virus* (HIV) diperlukan dan menentukan pengertian status HIV atau mengungkapkan status HIV dapat meningkatkan kepatuhan terhadap pengobatan dan mencegah penularan sekunder. Penelitian ini bertujuan mengetahui prevalensi serta faktor yang berhubungan dengan pengungkapan status HIV pada anak yang terinfeksi HIV. Penelitian dengan desain potong lintang dengan 44 pasangan anak-pengasuh terinfeksi HIV di poliklinik anak Rumah Sakit Umum Pusat Sanglah bulan Pebruari sampai Mei 2015. Peserta penelitian adalah pasangan anak-pengasuh yang terinfeksi HIV usia 5 sampai 12 tahun. Analisis data menggunakan SPSS 22, statistik menggunakan uji *Chi-square* dan nilai  $P \leq 0,05$  dan koefisien interval 95% dianggap signifikan. Prevalensi pada 19 anak (43,2%) telah

diungkapkan status HIV secara parsial dengan rerata usia adalah 7,7 (SB 2,33) tahun. Dalam analisis univariat status yatim piatu yaitu anak yang yatim piatu status HIV lebih sering diungkapkan dibanding anak yang tidak yatim piatu (OR 0,28; 95% CI 0,077 sampai 1,02;  $P = 0,049$ ). Tidak ada hubungan signifikan antara stadium klinis HIV, usia dan status pendidikan pengasuh dengan pengungkapan status HIV. Setelah analisis multivariat, hanya pengasuh yang bukan orangtua kandung memiliki hubungan terhadap pengungkapan status HIV pada anak-anak (OR: 15,6; IK 95% 1,48 sampai 164,3;  $P = 0,022$ ). Prevalensi pengungkapan status infeksi HIV pada anak adalah 43,2% dengan pengungkapan parsial, pengasuh yang bukan orangtua kandung merupakan faktor yang berhubungan dengan pengungkapan status HIV pada anak.

**Kata kunci:** *pengungkapan status HIV, human immunodeficiency virus, pengasuh, anak-anak*

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## ABSTRACT

A comprehensive management of *human immunodeficiency virus* (HIV) infection is necessary. Another important challenge is determining the HIV status understanding or disclosing HIV status which can further enhance the adherence to treatment and preventing secondary transmission. The aims of the study were to know the prevalence of HIV status disclosure and factors associated with HIV status disclosure in children. This was a cross-sectional study comprised of 44 caregivers of children with HIV infection at pediatrics outpatient Sanglah Hospital was conducted from February until May 2015. The study participants were caregivers of HIV-infected children age 5 to 12 years. Data analysis was using SPSS 22, statistics using Chi-square test and P-values  $\leq 0.05$  and 95% CI were considered significant. The prevalence was found 19

children (43.2%) who had partially disclosed their HIV status, with mean age was 7.7 (SD 2.33) years. In univariate analysis, the orphans were more likely to have their status disclosed compare to those who are not orphans (OR 0.28; 95% CI 0.077 to 1.02;  $P = 0.049$ ). There were no significant relations found between HIV clinical stage, nutritional status of the children, the caregivers age, educational status of the caregivers with HIV status disclosure. After multivariate analysis, only non-parent caregivers were associated with HIV disclosure status (OR: 15.6; 95% CI 1.48 to 164.3;  $P = 0.022$ ). Based on this study we conclude the prevalence of HIV disclosure status was 43.2% with partial disclosure status, non-parent caregivers was a factor associated to HIV disclosure status.

**Keywords:** *disclosure HIV status, human immunodeficiency virus, caregiver, children*

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## INTRODUCTION

At the end of 2010, the World Health Organization (WHO) estimated there were 3.4 million children less than 15 years old living with the human immunodeficiency virus (HIV), while an estimated

390,000 children were newly infected.<sup>1</sup> An estimated 180,000 children under 15 years old were living with HIV in the Asia-Pacific in 2010.<sup>2</sup> Based on 4045 children in the data base from six countries

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enrolled through March 2011, 31% were adolescents (12 years of age or above), and 53% of them were female.<sup>3</sup>

A comprehensive management of HIV infection is necessary. Another important challenge is determining the HIV status understanding or disclosing HIV status which can further enhance the adherence to treatment and preventing secondary transmission promoting overall physical and mental health.<sup>4,5</sup> Human immunodeficiency virus (HIV) status disclosure here means the process of revealing a child's HIV status. There are three types of status disclosure such as non disclosure, partial disclosure and complete disclosure. The decision to disclose an HIV status to a child is difficult and emotion-laden. However, HIV status disclosure is crucial for a long term disease management, hence it should be started when ever possible.<sup>5,6</sup>

Study for review by Pinzon-Iregui et al,<sup>7</sup> reported that prevalence of disclosure was 20% in studies conducted in low and middle income countries

(LMIC) and 43% in high-income countries. Median age of disclosure was 9.6 years in LMIC and 8.3 years in high income countries. Biadgilign et al<sup>8</sup> study in children age 1-14 years in Ethiopia, reported that prevalence of disclosure was 17.4%. Moodley et al<sup>9</sup> in children age 0-11 years in South Africa reported prevalence of disclosure 9%.

Study for disclosure in HIV Thai children by Boon-Yasidhi et al<sup>10</sup> in 2005 children aged 5 years and older had prevalence is 19.8%. Age for disclosure of HIV status is 5 years and older although at the age of 2 years disclosure HIV can be done.<sup>6</sup> Disclosure HIV status at the age of two years usually with partial disclosure. In 5 years, children start to understand the role of beliefs in predicting and explaining action.<sup>11</sup> Systematic review by Vreeman<sup>5</sup> all in 2013 is proportion of disclosed children range from 0 to 69.2%. Some important factors influencing the status disclosure include the child's and caregivers factors.<sup>5</sup> The objective of the study were to know the prevalence of HIV status disclosure and factors associated with HIV status disclosure in children and caregivers at Sanglah Hospital, Denpasar.

**Table 1 Demographic characteristic of children based on disclosure status (N=44)**

Variable	Disclosure status	
	Disclosed n (%)	Not Disclosed n (%)
<b>Age</b>		
Mean (SD)	7.7 (2.33)	7.34 (2.01)
95% CI	CI : 6.66 to 8.92	CI : 6.50 to 8.17
<b>Age (years)</b>		
Pre adolescent (5-10)	16 (36.4%)	22 (50%)
Adolescent (11-12)	3 (6.8%)	3 (6.8%)
<b>Sex</b>		
Male	10 (22.7%)	15 (34.1%)
Female	9 (20.5%)	10 (22.7%)
<b>Orphanage</b>		
Non orphan	5 (11.4%)	14 (31.8%)
Orphan	14 (31.8%)	11 (25%)
<b>WHO clinical stage*</b>		
Stage I	18 (40.9%)	21 (47.7%)
Stage II	1 (2.3%)	4 (9.1%)
<b>Nutritional status</b>		
Normal	18 (40.9%)	22 (50%)
Malnutrition	3 (6.8%)	1 (2.3%)
<b>ART regimen</b>		
On ARV	18 (40.9%)	25 (56.8%)
Not on ARV	1 (2.3%)	0 (0%)
<b>Duration of clinic attendance /diagnose HIV (month)</b>		
Less than 12	2 (4.5%)	4 (9.1%)
12 and above	17 (38.6%)	21 (47.7%)
<b>Duration of treatment (month)</b>		
Less than 12	1 (2.3%)	4 (9.1%)
12 and above	17 (38.6%)	21 (47.7%)

\*; no patient with Clinical stage III & IV in our sample

## MATERIALS AND METHODS

This was a cross-sectional hospital based study. The study population comprised of 44 parents/caregivers with child who undergo treatment for HIV infection at pediatric outpatient Sanglah Hospital. The study was conducted from February until May 2015. The study participants were included when they were HIV infected children age 5-12 years old and their caregivers age were 20 years old and above. The exclusion criteria include caregiver didn't willing to participate and didn't agree sign informed consent.

Study participants were recruited based on consecutive sampling with proportion study in Thailand disclosed is 19.6%.<sup>12</sup> In this study we calculated the sample size based on nominal data, a single sample to estimate the proportion of a population, use  $P < 0.05$  as a significance degree and we found minimum sample size for this research was 44 samples.<sup>13</sup> Structured questionnaires were used to collect information on children and caregivers's characteristic. Our outcome of interest was prevalence and factor's associated of HIV status disclosure in children.

Data was processed and analysed using SPSS. Association between categorical of variables was tested using Chi-square test and p-values less than 0.05 and confident interval 95% were considered significant. This study was approved by Ethical Committee of Udayana University Medical School/Sanglah Hospital Denpasar. Demographic

characteristic of children based on disclosure status is presented in Table 1.

## RESULTS

There were 44 children involved in this study, male 25 (56.8%) with mean age 7.4 years old. Prevalence of pre adolescent age was 86.4% with age disclosure was 7.7 years (SD 2.33; range 5-12) years. In our study we found orphanage status 56.8%, HIV stage 1 was 88.6%, well nourished was 90.9%. In this study we found on ARV regimen (97.7%) and

just 2.3% no regimen ARV because CD4 > 350. Duration diagnosed and on treatment with HIV one year and above was 86.3%. Of total HIV status was disclosed, 47.3% had disclosed one year or above. Characteristic of caregiver based on disclosure status is presented in Table 2.

Age caregiver range 23-62 years old, age caregivers disclosure is 35.74 (SD 7.51) years old. Caregivers who are older than 35 years old were 34.1% with educational status of senior high school and above were 70.4%. Non-parent caregivers were 40.9% with 20.5% was raised by someone else (foundations). There were 19 children (43.2%) with totally partial disclosure with reason, 25 children (56.8%) non disclosed their HIV status with the reasons of health and the belief that child was not ready or too young were found 18 children (40.9%), subsequent stigma were 5 children (11.4%), concern for child emotional or physical were 2 children (4.5%). Association between child factors and disclosure status are presented in Table 3.

Based on caregivers report, 19 children-caregiver pair (43.2%) had disclose their HIV status, with totally partial disclosure and the mean age was 7.7 years (SD 2.33) and 25 children (56.8%) non disclose their HIV status with mean age 7.34 (SD 2.01) years old. There was no significant difference in HIV status disclosure either among male and female (P=0.74) and duration of clinic attendance (P=0.6). Orphan status were more likely to have their status disclosed than not orphan (OR 0.28; 95% CI 0.077 to 1.02; P =0.049). Association between caregiver factors and disclosure status are presented in Table 4.

The age of the caregivers were ranged from 23 to 62 years old with mean age caregivers disclosure is 35.74 (SD 7.51) years. There was no significant different of the age of the caregiver to the status disclosure (P=0.34) and no significantst different for educational status for disclosure status HIV (P=0.68). Non-parent caregiver related to the disclosure of HIV status were 13 children (29.5%) with (OR:8.67; 95% CI: 2.19 to 34.35; P=0.001). Factor associated with HIV disclosure status are presented in Table 5.

Out of two variables with P values less than 0.05, only one variable had statistical significance after multivariate logistic regression test. Non-parent caregiver is aassociation with HIV infected status disclosure in children.

## DISCUSSION

This prevalence was specifically based on the age of more than 5 years old. In the total HIV infection in the population, there was distributed more to those under 5 years old age group in which discussion

**Table 2 Characteristic of caregiver based on disclosure status (N=44)**

Variable	Disclosure status	
	Disclosed n(%)	Not Disclosed n(%)
<b>Age</b>		
Mean (SD)	35.74 ( 7.51)	36.76 ( 9.65)
95% CI	CI : 32.11 to 39.36	CI : 32.78 to 40.74
<b>Age (year)</b>		
20-35	14 (31.8%)	15(34.1%)
Older than 35	5 (11.4%)	10 (22.7%)
<b>Educational level</b>		
≥ senior high school	14 (31.8%)	17 (38.6%)
<senior high school	5 (11.4%)	8 (18.2%)
<b>Caregiver</b>		
Parent	6 (13.6%)	20 (45.5%)
Non parent	13( 29.5%)	5 (11.4%)
<b>Caregiver-parent</b>		
Parent complete	5 (11.4%)	13 (29.5%)
Parent not complete	1 (2.3%)	7 (15.9%)
<b>Caregiver_non parent</b>		
Family	4 (9.1%)	4 (9.1%)
Others	10 (22.7%)	0 (0%)

**Tabel 3 Association between child factors and disclosure status (N=44)**

Variable	Disclosure status		P value	OR (95% CI)*
	Disclosed n (%)	Not Disclosed n (%)		
<b>Age (years)</b>				
Pre adolescent (5-10)	16 (36.4%)	22 (50%)	0.717	1.37
Adolescent (11-12)	3 (6.8%)	3 (6.8%)		(0.24 to 2.47)
<b>Sex</b>				
Male	10 (22.7%)	15 (34.1%)	0.625	0.74
Female	9 (20.5%)	10 (22.7%)		(0.22 to 0.47)
<b>Orphanage status child</b>				
Not orphan	5 (11.4%)	14 (31.8%)	0.049	0.28
Orphan	14 ( 31.8%)	11 (25%)		(0.077 to 1.020)
<b>Duration of clinic attendance</b>				
Less than 12 month	2(4.5%)	4(9.1%)	0.6	0.618
12 month and above	17 (38.6%)	(47.7%)		(0.1 to 3.8)

\*:analysis with X<sup>2</sup> test, p < 0.05 with 95% CI

**Table 4 Association between caregiver factors and disclosure status (N=44)**

Variable	Disclosure status		P value	OR (95% CI)
	Disclosed, n (%)	Non Disclosed, n (%)		
<b>Age (year)</b>				
20-35	14 (31.8%)	15 (34.1%)	0.343	1.867
Older than 35	5 (11.4%)	10 (22.7%)		(0.51 to 6.83)
<b>Educational status</b>				
≥ senior high school	14 (31.8%)	17 (38.6%)	0.682	1.318
< senior high school	5 (11.4%)	8 (18.2%)		(0.35 to 4.94)
<b>Caregiver</b>				
Non parent	13 (29.5%)	5 (11.4%)	0.001	8.67
Parent	6 (13.6%)	20 (45.5%)		(2.19 to 34.35)

\*: analysis with X<sup>2</sup> test, P < 0.05 with 95% CI

**Table 5 Factor associated with HIV disclosure status**

Variable	P value	OR (95% CI)
Orphan status	0.486	2.31 (0.22 to 24.32)
Caregiver	0.022	15.6 (1.48 to 164.3)

\*; analysis with multivariate logistic regression

about HIV status disclosure almost impossible to be done. The total population of HIV infected children was 153 person. Age group divided into under one year old was 16 (10.4%), 1 to 4 years old was 86 (49.7%) and 5 years old and above was 61 person (39.9%).

Disclosure refers to the process of revealing a child's HIV status. There are three types of status disclosure such as non disclosure, partial disclosure and complete disclosure.<sup>5,17</sup> Non disclosure type could possibly happen if the caregivers do not want to disclose the child's HIV status.<sup>5</sup> Partial disclosure may be an effective strategy to help caregivers who are not ready to use the term HIV and AIDS. Partial disclosure involve teaching a child about his/her body and how the immune system works before using the actual words HIV and AIDS, for example; red virus attacking my body, the child knows that he/she is sick but does not know that it is HIV infection. For instance, a child with age related cognitive limitations may be told that it has few and weak soldiers to defend the body because of attacks by 'bad guys'.<sup>17</sup> Complete disclosure means that the child knows his/her HIV status and has been told about the disease information and the caregivers already naming HIV and ways of transmission.<sup>5,6</sup>

Age related cognitive limitation was consider to those who are 5 years old and above. In 5 years, which is considered to be the time of cognitive maturation and hence the right time for disclosure,

children start to understand the role of beliefs in predicting and explaining action. Specifically, at this age, children have the critical insight that another person could hold a belief that is false, that is different from their own, and that will result in a particular action.<sup>11</sup>

Our study found the prevalence was 43.2% of children know their HIV-status. This HIV status disclosure however was overall from the partially disclosure type. The prevalence of 43.2% consistent with studies in California (USA) (43.1%),<sup>14</sup> Ghana (21%),<sup>15</sup> Thailand (19.8%),<sup>10</sup> and Ethiopia (17.4%)<sup>8</sup> was higher than the findings reported in South Africa (9%).<sup>9</sup> The reasons for these variations was in South Africa the study population included children of younger age (5 months to 11 years), as opposed to that of our study participants (5 to 12 years).

The findings were different in the level of disclosure in our study is higher than Thailand because in our study we did not confirm the children how to understand children's HIV status disclosure. The high number of disclosure in this study with limited disclosure is only partial because the majority of the sample was preadolescent. The high level of disclosure in the United States may be due to socio-cultural differences indicate higher levels of expression in the family and more intensive parent-child interactions,<sup>14</sup> which is not the case in most African countries, including Ethiopia.<sup>8</sup>

The average age of 7.79 years disclosure is different from 9.2 years, were reported in Thailand this age.<sup>16</sup> The reason for the disclosure in our setting may be due to the lack of disclosure protocol in the setting and parents / caregivers reluctance to initiate disclosure. Regarding the reason for not disclosing their HIV status to children, caregivers reported that the disclosure does not occur because the children are health and belief that the child is not ready or too young or not emotionally mature enough to deliver a message about HIV, and can lead to negative emotional consequences such as stigma, become psychologically affected. These reasons are consistent with previous findings from Thailand.<sup>16</sup>

In our study, orphan status associated with the disclosure of HIV status, when the patient orphanage is associated with disclosure status HIV. However after logistic regression analysis obtained non parent caregiver as associated with disclosure HIV infected in children. Non-parent caregiver has a association to disclosure, because when children raised by biological parents, parents will try to cover his HIV status and to protect children from discrimination and parental guilt.

The average age of the already revealed his disclosure HIV status is 7.7 years. This is in contrast



to other studies that obtain disclosure on the age  $\geq 11$  years of age, here because the samples were mostly preadolescent age here that does not give a significant difference to the status disclosure. Most parents/ caregivers in other study preferred to disclosure when the child enters adolescence, ie at an average age of 11 years and above.<sup>5,17</sup>

Caregivers who proposed the age mid-teens believe that it is the age at which children are emotionally mature enough to cope with chronic illness and need sex education to prevent the spread of infection. However, their arguments may be at risk due to the mid teens they may actually already engaged in sexual activity and without knowing their status, the risk of transmission, and thus disclosure should occur before that age.<sup>17</sup>

We found that 31.8% caregiver age younger than 35, caregiver age and educational status here does not differ significantly towards status disclosure. We believe that the disclosure is an ongoing process, commensurate with the child's age and maturity. Starting with the partial disclosure and be on time complete disclosure. We want to encourage further research directed at the psychological aspects of assessment, knowledge and long-term sequelae of the children in both groups was disclosed and non-disclosed.<sup>17</sup>

Limitation our study is the prevalence of HIV disclosure may actually be lower because more of the population died before there search can not be used as a sample as well as the status of disclosure totally partial disclosure. Our study do not confirm again how the child will understand the status of the disease because most of the samples preadolescent where cognitive maturity level is limited and can not assess in the abstract. Further research is needed to confirm HIV status by asking directly to the children and to guardians.

## CONCLUSION

Prevalence disclosure of HIV status to children 43.2%, but this disclosure totally partial disclosure because most samples were preadolescent age, where they are less mature emotionally, intellectually. Non-parents caregivers as associated to the HIV infected children status disclosure.

Efforts should be made to develop a protocol for the disclosure of health care providers, and parents/ caregivers should be involved in developing disclosure protocols. Health care providers should be encouraged to have a formal discussion and also to provide health education and sensitization of the public to alleviate stigma and discrimination. Parents / caregivers should be empowered disclosure process technique.

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