

Challenges and social support provisions in the treatment of HIV infected children in Indonesia

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Yuyun Yuniar, Rini Sasanti Handayani

Research and Development Center for Health Resources and Services, National Institute of Health Research and Development, Ministry of Health, Jakarta, Indonesia

Corresponding address: Yuyun Yuniar

Email: yuyunyuniar2018@gmail.com

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Abstrak

Latar belakang: Pengobatan pada anak yang terinfeksi HIV merupakan tantangan bagi para orang tua/pengasuh karena berbagai permasalahan menyangkut kesehatan mereka.

Metode: Penelitian untuk mengeksplorasi pengalaman dan dukungan sosial pada pengobatan anak terinfeksi HIV dilakukan di 5 provinsi di Indonesia dengan prevalensi HIV tertinggi. Total sampel anak sebanyak 239 orang dari sejumlah 267 orang yang direncanakan. Data dikumpulkan dengan wawancara semi terstruktur dengan orang tua/pengasuhnya. Analisis dilakukan terhadap 165 anak berusia 1-14 tahun yang telah mendapatkan terapi obat antiretroviral.

Hasil: Dari sejumlah 165 anak, sebanyak 63,6% anak mengkonsumsi 1-2 item obat dan 36,4% mengkonsumsi 3-5 item. Efek samping yang paling sering terjadi adalah kulit kemerahan, mual dan muntah. Kesulitan yang paling sering dihadapi adalah rasa bosan dan anak mempertanyakan minum obat pada kelompok anak yang berusia 5-14 tahun. Orangtua/pengasuh berusaha melanjutkan pengobatan dengan mengingatkan jadwal minum obat, membujuk, memberikan penjelasan bahkan memaksa atau mengancam mereka untuk minum obat. Kesulitan tersebut makin bertambah seiring meningkatnya usia anak. Dukungan yang paling sering berasal dari orang tua dan keluarga besar seperti nenek atau paman, khususnya untuk anak yang sudah yatim.

Kesimpulan: Pemahaman hambatan pengobatan pada anak terinfeksi HIV dapat membantu untuk menyediakan intervensi yang tepat untuk meningkatkan kepatuhan yang akan mendorong kesuksesan terapi mereka. (*Health Science Journal of Indonesia 2019;10(2):103-10*)

Kata kunci: anak terinfeksi HIV, antiretroviral, dukungan sosial, pengobatan, kesulitan

Abstract

Background: The treatment of HIV infected children is a challenge to their caregiver due to many existing problems related to their health.

Methods: A research to explore the experience and social support on the treatment of HIV infected children was conducted in 5 provinces in Indonesia with highest prevalence of HIV. Total children sample was 239 out of previous 267 planned. Data was collected through semi structured interviews with caregivers of the children. The analysis was conducted to 165 children aged 1-14 years old who were on antiretroviral therapy.

Results: Among those 165 children, 63.6% took 1-2 items of medicines and 36.4% took 3-5 items. The most frequent adverse events were skin rash followed by nausea and vomiting. Boredom and questioning were the most frequent difficulties experienced by children aged 5-14 years old. The caregivers attempted to continue the treatment by reminding the children on schedule to take medicines, wheedling, explaining, forcing or even threatening them. The difficulties appeared more as the children grew older. The most frequent supports mainly came from parents, and extended family such as grandmother or uncle especially for orphaned children.

Conclusion: Understanding obstacles in HIV infected children will help to do proper interventions to improve adherence that will lead to successful therapy. (*Health Science Journal of Indonesia 2019;10(2):103-10*)

Keywords: HIV infected children, antiretroviral, social support, treatment, difficulties

The ministry of Health predicted the escalation of Human Immunodeficiency Virus- Acquired Immune Deficiency Syndrome (HIV-AIDS) infection in children due to the escalation of new HIV infection in women, especially housewives. The number of housewives infected up to April 2017 was 12,302 that reached the highest proportion among other types of occupations. According to the report per April 2017, the number of HIV infection during 1987 to April 2017 in <1 year was 307 (0.4%), age 1-4 years old was 1,650 (1.9%), age 5-14 years old was 1,042 (1.2%) and age 15 – 19 years was 2,355 (2.7%). It was predicted that 76.7% of children age \leq 14 years receiving Antiretroviral (ARV) of those who were eligible for therapy. The prevention mother to child transmission program (PMTCT) has been established, but the results were not yet optimal. Addressing social problems of stigma, discrimination, misconceptions and male involvement must be the part of PMTCT package.¹⁻³

HIV-AIDS treatment is a lifelong treatment so that the continuity of treatment affects the outcome of treatment. The aims of antiretroviral (ARV) treatment are to reduce morbidity and mortality associated with HIV, improve the quality of life of people living with HIV-AIDS, restoring and maintaining immune function, maximizing virus replication suppression as long as possible.⁴ HIV infected children are more vulnerable to treatment access because they have not been independent and often become a burden on family or relatives because their parents have died of HIV-AIDS.

Child Protection Act stated that every child has the right to live, grow, develop and participate fairly in accordance with human dignity, as well as protection from violence and discrimination. Countries and governments are obliged and responsible for providing infrastructure support in the implementation of child protection. HIV infected children and stigmatized children caused by their parents' status are stated in article no 59 as those who are eligible to have special type of protection by conducting appropriate monitoring, prevention, cure, treatment and rehabilitation program.⁵ Thus, HIV infected children treatment program is considered as a form of children protection.

Studies conducted by UNICEF and the National AIDS Commission indicate the difficulties faced by children infected with HIV-AIDS to access education and health services due to discrimination, family's financial hardship, worsen child health and

the need to care for the elderly who were also HIV-AIDS positive.³ Lack of assistance on nutrition, monitoring and forgetfulness to take ARV caused poor adherence.⁶ The caregivers of HIV positive children in poor conditions showed a high level of stress.⁷ Approximately 90% of about 3.4 million HIV infected children lived in sub-Saharan Africa, and more than 500 thousand were infected through perinatal process. The implication is on the need to have adequate care and treatment. Since the use of antiretroviral treatment (ART), those children with access to ARV can live longer and healthier lives into adolescence and adulthood. Therefore, pediatric HIV care programs should shift its focus from survival to addressing children's physical and psychosocial wellbeing. The presence of parents who take care of the children, involving psychosocial interventions during treatment and expanding family support center indicated as the factor for successful treatment.⁸⁻¹⁰ This study aims to explore the challenges faced by children and their caregiver during ARV therapy and the efforts of caregiver to support adherence.

METHODS

Data sites

Based on the report, the sites of data collection were in five provinces with high prevalence of HIV in Indonesia with consideration of west to east areas. The three monthly reports of Directorate general of Disease Prevention and Control in 2013 stated that the number of HIV-AIDS cases mostly located in DKI Jakarta, East Java, Papua, West Java, Bali, North Sumatera, Central Java, West Borneo, Riau Island and South Sulawesi provinces. We selected five provinces with highest number of cases except for West Java as it is located close to DKI Jakarta which has been chosen. In each province was chosen as a city and a district. The provinces were DKI Jakarta (West Jakarta and North Jakarta), East Java (Surabaya and Malang), Bali (Denpasar and Buleleng), North Sumatera (Medan and Deli Serdang) and Papua (Jayapura city and Jayapura district) as listed in table 1. Data was collected from March-July 2015. The data was part of a research entitled Akses Pengobatan HIV-AIDS dan Infeksi Oportunistik pada Anak di Sepuluh Kabupaten/Kota di Indonesia (Access to HIV-AIDS and Opportunistic Infection Treatment of Children in Ten Districts in Indonesia).

Data collection

Based on the classification that children are those age less or similar to 19 years old, we considered

prioritizing the guardians/caregivers as the main informants. The sample was the guardians/caregivers of children with HIV-AIDS aged less or similar to 19 years old. Children aged 15 or more with ability to answer by themselves were also eligible for sample informants. Therefore, the respondent can be the caregivers or the children themselves depend on the age of children. The number of caregiver of children to be interviewed was based on the number of children with HIV-AIDS as reported in the district health offices in ten districts sample areas, regardless the possibility of caregivers with more than one HIV positive children. The guardians were interviewed personally by the researcher using semi structured interview form. In addition to those caregivers, relevant health care providers and nongovernmental organizations (NGO) staff were also been interviewed using in depth interview form.

The number of guardians/caregivers was counted based on the number of reported HIV cases in children using the formula¹¹:

$$n = \frac{Z^2 P(1-P)}{(d)^2}$$

n = sample size Z = 1.96 P = 50 % d = 0.06

The number of samples was 267 respondents. The number of samples in each district decided using proportional sampling method.

$$n1 = \frac{n \cdot N}{N1}$$

n1 = proposed sample in district 1; n = sample number in district 1; N = number of total sample (267); N1 = total population (517, based on national report)

Table 1. Number of sample reported, proposed and interviewed (0-19 years old)

NO	Province	District	N reported	N proposed	N sample	% response rate
1	DKI Jakarta	North Jakarta	71	39	45	115,38
		West Jakarta	35	17	21	123,53
2	East Java	Surabaya City	87	46	44	95,65
		Malang District	36	17	16	94,12
3	Bali	Denpasar City	51	28	24	85,71
		Buleleng District	16	9	19	211,11
4	Papua	Jayapura City	93	45	22	48,89
		Jayapura District	44	25	15	60,00
5	North Sumatera	Medan City	76	35	22	62,86
		Deli Serdang District	8	6	11	183,33
Total guardians/caregivers			517	267	239	89,51

Data analysis

Due to consideration that the range of age with vulnerability of transmission from mother was 1-14 years old which was also the category of age used by ministry of Health in its report, we only analyzed caregivers who have children 1-14 years old. The problems of treatment mostly happen in those who were on antiretroviral (ARV) therapy. Therefore, a further analysis was conducted for those aged 1-14 years old and also on ARV. As a result, those aged less than 1 year or more than 14 years (who were interviewed directly) were excluded in the analysis.

The variables to be analyzed were characteristics of children including age groups and number of drugs taken; caregivers' status including education, occupation, and relationship with children. Variables related to ARV treatment were viewed on two sides: adverse events and challenges

impeding treatment, and social support to continue treatment. Both inhibiting and supporting factors were analyzed using quantitative and qualitative methods. We collapsed the characteristic, adverse events, challenges, and social support form and sources into frequency distribution table which also completed with qualitative analysis based on verbal narration of the caregivers. Quantitative data were analyzed using SPSS v.18 to present the frequency distribution characteristic and bivariate analysis on the relationship between children and caregiver characteristics with compliance of period to refill the medication; the relationship of children characteristics with adverse events and impediments; and also the relationship of caregiver status with supporting efforts. Qualitative data resulted from in depth interviews with the health care providers and NGO staff were analyzed descriptively as an addition to quantitative data.

Ethical approval

Ethical approval was obtained from the Institutional Review Board in National Institute of Health Research and Development, number LB.02.01/5.2/KE.071/2014.

RESULTS

Characteristic of children

The number of children aged 1-14 years old who were on ARV was 165 among all 239 samples. Most caregivers interviewed were the biological parents, mainly the mothers. The site of living, characteristics of the children, number of drugs items taken, caregivers' education status, house status and relationship with children are listed in table 2.

Table 2. Characteristic of children and caregivers

Characteristic	N	%
District		
North Jakarta	35	21.2
West Jakarta	21	12.7
Surabaya City	30	18.2
Malang District	6	3.6
Denpasar City	21	12.7
Buleleng District	16	9.7
Jayapura City	4	2.4
Jayapura District	3	1.8
Medan City	22	13.3
Deli Serdang District	7	4.2
Age range		
1-4 years	46	27.9
5-14 years	119	72.1
Number of drugs taken		
1-2 items	105	63.6
> 2 items	60	36.4
Education of caregivers		
Up to junior high school	82	49.7
Senior high school and up	83	50.3
Occupation of caregivers		
Housewives/unemployed	80	48.5
Employed	85	51.5
Relationship with children		
Biological parents	109	66.1
Extended family or others	56	33.9
Compliance on routine medication refill		
At least every month	161	97.6
More than one month/irregular	4	2.4
Total	165	100

Compliance on routine medication refill

Bivariate analysis is conducted in order to find out the relationship between characteristic and compliance. The limitation of this research did not directly measure compliance on taking medication in

detail by counting the leftover medication or asking how many times they did not take ARV. The standard period of refill medication regularly is usually one month. Therefore, those who went to health facilities less than once a month are considered as having the possibility of incompliance. Yet the proportion of children who were considered comply in refilling the medicine was 97.4%. This proportion is too high to find a correlation between those who complied and those who did not. The analysis showed in table 3.

Table 3. The relationship between characteristic and compliance on routine medication refill

Characteristic	Comply on routine medication refill n	%	Exact Sig (2 sided)
Characteristic of children			
Age range			
1-4 years	44	95.7	0.310
5-14 years	117	98.3	
Number of drugs taken			
1-2 items	102	97.1	1.000
> 2 items	59	98.3	
Characteristic of caregivers			
Education			
Up to junior high school	81	98.8	0.620
Senior high school and up	80	96.4	
Occupation			
Housewives/not working	78	97.5	1.000
Working	83	97.6	
Relationship with children			
Biological parents	105	96.3	0.301
Extended family or others	56	100.0	

As predicted, the result shows that there is no significant factor of compliance to refill the medication, neither characteristic of children nor characteristic of caregivers.

Challenges

In addition to a number of drugs that should be consumed by children as listed in table 2, the adverse event was also one of the barriers to regular treatment. Experienced adverse events can be more than one type. Reported adverse events and faced challenges are listed in table 4.

Despair was experienced by some children and parents. Parents desperate when they should give bitter medicine in children under 5 years due to the unavailability of pediatric dosage form. The desperation could possibly lead a low level of adherence to stop taking medication.

“[When they] Got a problem, then despair, the parents are deceased, for what life is, what to do anyway [as] I have an illness like this, I shall pass [away].” (NGO, Surabaya)

The parents’ discipline to take the drug from hospitals was still lacking and many patients who went half-

heartedly so often end up in drop out, especially when experiencing side effects.

“The HIV positive parents are lazy to take medicines, so the children do not take it also. They said they surrender, alive or dead is up to God.” (NGO, Kab. Malang)

Table 4. Challenges in children’s treatment

Aspects	Number of drugs taken				Exact Sig (2 sided)	Age range				Exact Sig (2 sided)
	1-2 items		> 2 items			1-4 years		5-14 years		
	n	%	n	%		n	%	n	%	
Adverse event										
Nausea/vomiting	14	13.3	12	20.0	0.274	7	15.2	19	16.0	1.000
Dizziness	10	9.5	4	6.7	0.772	1	2.2	13	10.9	0.115
Fatigues/drowsiness	13	12.4	8	13.3	1.000	3	6.5	18	15.1	0.193
Insomnia	14	13.3	4	6.7	0.299	4	8.7	14	11.8	0.782
Skin rash	27	25.7	18	30.0	0.558	10	21.7	35	29.4	0.436
Anemia	3	2.9	6	10.0	0.074	1	2.2	8	6.7	0.447
Challenges										
Boring	40	38.1	21	35.0	0.739	11	23.9	50	42.0	0.033*
Forgetfulness	9	8.6	8	13.3	0.425	1	2.2	16	13.4	0.043*
Hard to swallow / vomiting	9	8.6	11	18.3	0.083	9	19.6	11	9.2	0.107
Keep questioning	40	38.1	21	35.0	0.739	8	17.4	53	44.5	0.001*

Table 4 shows the relationship of number of drugs taken and age range of children with adverse events and challenges (impediments) happened. It can be concluded that number of drugs taken has no significant influence on adverse events and challenges. Contrarily, age range shows several significant influences challenges aspect. Older children faced more adverse events and challenges in taking ARV. Older children can express their feeling better than younger children. The same assumption might also for boredom and forgetfulness, in which older children experienced them more frequently. Meanwhile keep questioning on why they have to keep taking medication possibly happened to older children as they can ask. The older the age of children the more they think about why they must take the medication while others don’t. Younger children can be forced to take medication. Even though it is not significance but the problem of hard to swallow or vomiting happened more frequently in younger children due to bitterness or tablet dosage form.

Social Supports

Support to sustain regular treatment was done in various ways. The support can be more than one way and the source of support can be derived from more than one source. The caregivers admitted various sources of support which comes mostly from family

(75.2%), NGOs/peer groups (51.5%), caregivers’ spouse (47.9%), and healthcare providers (44.8%). The relationship of caregivers characteristic and the form of social support are listed in table 5.

Some children do not experience difficulty in taking medications, especially babies because they could not refuse. However some children must be persuaded or even forced by 3 adults in a case. Most parents try to give medication regularly and some HIV-positive parents gave their own example by taking medicine to induce the child to imitate them. Social support came mostly from family although initially one or more family members deny or discriminate against his/her own HIV positive family.

“Initially there was shocked, but slowly they will think again who else if not me that support. If you already know, most of the support and compassion came from them.” (NGO, Jakarta Barat)

“Children are the nation’s capital, so they must be handled properly” (hospital physician, Kota Denpasar)

“K is the same with her father; she exactly knows that she doesn’t want to be like her father as her father has passed away.” (NGO, Kab. Buleleng)

“Just don’t ever, ever there will be a story that there were curly black haired people in Papua”. (NGO Kab. Jayapura)

The last quote implies a very deep concern and worries about the future existence of Papua people. If HIV-AIDS continues to spread out in general population, more and more people die due to AIDS, then in the future Papua people will be left as history.

Various forms of social support already existed in the form of support from government agencies or NGOs. Various NGOs have been exist in each district / city with specialty in handling HIV children, certain groups of people living with HIV and people living

with HIV in general. In Buleleng NGO volunteers took ARV to health centres or referral hospitals. Some volunteers and health workers also provided home visits to monitor the treatment of patients.

Social support from the community, among others were the existence of groups such as AIDS care community in East Java and village cadres concerned with AIDS community and students care with AIDS and Drugs community in Bali. In Papua there are traditional leaders and religious leaders who have been involved in HIV-AIDS. One of the advantages in Papua is their chiefs (Ondo Api) who were very supportive by approaching the traditional leaders first.

Table 5. The forms of supporting efforts

Characteristic of caregivers	Category 1		Category 2		Exact Sig (2 sided)
	Housewives/ unemployed		Working/ Employed		
Working status	n	%	n	%	
The form of support					
Reminding	44	55.0	51	60.0	0.516
Persuading	39	48.8	47	55.3	0.400
Forcing/making scared of	14	17.5	9	10.6	0.200
Explaining	20	25.0	32	37.6	0.081
Education	Up to junior high school		Senior high school and up		Exact Sig (2 sided)
The form of support	n	%	n	%	
Reminding	52	63.4	43	51.8	0.694
Persuading	44	53.7	42	50.6	0.694
Forcing/making scared of	11	13.4	12	14.5	0.847
Explaining	24	29.3	28	33.7	0.532
Relationship	Biological parents		Extended family or others		Exact Sig (2 sided)
The form of support	n	%	n	%	
Reminding	59	54.1	36	64.3	0.211
Persuading	61	56.0	25	44.6	0.168
Forcing/making scared of	14	12.8	9	16.1	0.571
Explaining	36	33.0	16	28.6	0.560

Table 5 explored the relationship of caregivers’ characteristics and the form of efforts to support compliance on taking medication. Unfortunately there is no significant difference in types of efforts between caregivers with different characteristics.

DISCUSSIONS

Antiretroviral therapy for people living with HIV AIDS (PLHIV) is aimed to prolong the life of PLHIV as well as their quality of life. Due to lifelong treatment, adherence in the therapy process becomes a critical point of successful treatment.¹² Antiretroviral therapy in children also faces an adherence problem in regard to similar or different factors. In Ethiopia about 60% of eligible PLHIV have been treated by antiretroviral but

only 12% of children aged less than 15 years getting it because of data limitations and lack of awareness about the possibility of infection in children especially those who are older.¹³ This result showed similarity of problems in taking medication in older children even though they still comply with the therapy. There is no significant factor of adherence in term of number of pills, education background and occupation of caregivers and even the relationship of caregivers. This result is in accordance with previous research which showed that the predictors were not significantly influence adherence except the unavailability of caregivers.¹⁰

Children are considered as a vulnerable subject in which the success of the treatment highly depends on their caregivers. Estimated number of orphans because

their parents died due to AIDS in Ethiopia was about 800,000. Approximately 11.9% of the children infected with HIV-AIDS and mostly aged between 5-10 years were from infected parents but were not identified and does not have access to treatment.¹³ A key factor in compliance with ARV treatment in pediatric patients is the presence of biological parents who care for children.^{10,14} More PLHIV can be saved since the development of antiretroviral, so that fewer and fewer children are being orphaned and otherwise the children were raised by parents with the status of PLHIV even though some may be asymptomatic.¹⁵

Children and teenagers infected HIV from their parents is a challenge in HIV prevention because there is no comprehensive intervention concerning the problems of puberty, psychosocial and neurocognitive function.¹⁶ Many problems related to children's adherence have been identified from their caregivers ranging from an economic problems, stressful, forgetful, older caregivers, growing older children and ARV related problems.^{6, 7, 10, 17-20} ARV related problems might due to adverse events such as skin rash, nausea/vomiting and dizziness. Our result showed similar problem with previous research which mainly stated that boredom, forgetfulness and questioning children were the most common problems as the children growing older. The older the children are, the more questioning they are.

Sustaining the treatment becomes a challenge for caregivers. This study also highlights the efforts made by caregivers in the form of reminding schedule, persuading and sometimes attributed by forcing or threatening children to take medicines although there is no significant background factor from different approaches. Previous research also revealed the same attempts made, even in elderly caregivers.²⁰ The need for social support for caregivers and the children themselves is clearly shown which can be started from disclosing status and counselling program.^{21,22} Decreasing a burden through disclosing status proved to increase the success of treatment.^{8,23} In addition, our study also emphasized that the main source of support in children receiving ARV came from family either the biological parents or grandparents and extended family.

To conclude, maintaining adherence in children needs policies and programs addressing the problems shown. Interventions should include elements to improve the welfare of the school to reduce stigma and create a more supportive environment such as family support centres.⁹ Providing guidelines

for disclosing status and counselling are also needed to support the caregivers.^{10,24,25} Innovative interventions should enjoin education, counselling, provision of social support, directly observed therapy, and financial incentives. Some successful methods included reminder using text messaging and pillboxes.¹² In this case, parents can be equipped with pillboxes and also supported by NGO or health provider staff by using text messaging service or other feasible communication media.

Understanding the problem related to treatment and exploring the available social support is needed to identify the possible solutions. This research provides needed information about challenges and social supports. Difficulties on HIV infected children treatment mainly due to boredom and children questioning on long time medication. Efforts made by the caregivers by reminding or persuading the children to take medicines, yet support from family emerged as an important form of social support.

In conclusion, the treatment of HIV positive children is challenged by many problems such as the problem related to antiretroviral, psychosocial problem and other problems from caregivers. Boredom, forgetfulness and keep questioning on why they have to take the medication revealed as significant challenges in the treatment of older children (aged 5-14 years old). Successful treatment cannot be achieved unless relevant interventions involving all related sectors including government, health provider, NGOs and school are made for supporting the children and their families.

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