Determinant Factors affecting Quality of Life of Children with HIV/AIDS

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Abstract

HIV/AIDS causes physical problems, such as recurrent infections, growth disorders and malnutrition. HIV/AIDS also causes psychosocial problems, such as being shunned by friends and getting discriminatory behavior. All of the problems described earlier affect children's mental growth and development which will affect the quality of life of children with HIV/AIDS**.**

This research is a cross sectional study, conducted at the Intermediate Care Unit of Infection Disease of Children Outpatient Clinic in Dr. Soetomo General Hospital Surabaya and Voluntary Counselling and Testing Outpatient Clinic in Gresik General Hospital, Probolinggo General Hospital and Trenggalek General Hospital in November 2019-May 2020. Data collected was descriptively, then statistically analyzed by bivariate and multivariate analysis.

According to bivariate analysis, factors significantly related to quality of life of children with HIV/AIDS were age, monthly caregiver income, distance between diagnosis and therapy, immunological status, nutritional status and treatment adherence. Multivariate analysis showed that age (p=0,014, Odds Ratio [OR] 18,780, confidence interval [CI] 1,810-194,844) and treatment adherence (p=0,010, OR 7,823, CI 1,631-37,516) had a significant relationship with the quality of life of children with HIV/AIDS (p <0.05).

In conclusion, age, monthly caregiver income, distance between diagnosis and therapy, immunological status, nutritional status and treatment adherence are significantly related to the quality of life of children with HIV/AIDS. Age and treatment adherence have the most significant relation with the quality of life of children with HIV/AIDS .

Keywords: *Determinant factors, HIV infection, quality of life*

Introduction

Children with HIV/AIDS encounter some problems including physical, mental and social problems. Physically, children may experience recurrent infection, malnutrition, and growth disturbance. Children also may face mental problems, such as unconfident, fear, depression, anxiety, anger, desperation, social withdrawal or other emotions. Unsupportive social environments may give them discriminative behavior, excommunication, stigmatization, and rejection. Mental and social problems may cause distress and decrease of immune system that may worsen their condition.[1,2]

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Children's parents may also face problems in raising their children due to recurrent infection, growth disturbance, malnutrition, sadness, rejection, denial, guilt, anxiety, anger and other emotional feelings. Lack of affection given to children with HIV/AIDS may worsen children's condition.[1,4]

Previous research has analyzed several variables that may affect the quality of life of children with HIV/AIDS. Nevertheless, similar research is still hard to find in Indonesia. Therefore, this research was held to find determinant factors influencing the quality of life of children with HIV/AIDS so that intervention can be given to increase the quality of life.

Materials and Method

This research used cross sectional study and was held in Dr. Soetomo General Hospital in Surabaya, Gresik General Hospital, Probolinggo General Hospital, and Trenggalek General Hospital from November, 2019 to May, 2020.

Sampling method used was a total sampling technique, including pediatric HIV/AIDS patients meeting certain criteria. The inclusion criteria were children that had been diagnosed with HIV/AIDS, had results of CD4 test in the last 6 months, were able to fill the PedsQL questionnaire and agreed to sign the informed consent form. The exclusion criteria were patients that had other chronic diseases, had no CD4 test results in the last 6 months, and only filled less than half of PedsQL questions.

The independent variables analyzed were age, sex, caretakers, caretakers' income, caretakers' education, caretakers' job, first diagnosis, duration between being diagnosed and getting therapy, immunodeficiency, nutritional status, stage when diagnosed, adherence to therapy, availability of medical center, care provider, facilities and supplies, occurrence of opportunistic infection when being diagnosed, and antiretroviral (ARV) category. The dependent variable is quality of life assessed using PedsQL.

Patients qualifying the criteria were listed. Information for consent was explained to the subject and caretakers and an informed consent form was signed by the caretakers. Data needed were collected. Subsequently, subjects were asked to fill the PedsQL questionnaire.

Data collected were descriptively analyzed and presented in the form of table and graph. Variables were analyzed statistically using Chi square. Variables proven significantly related to quality of life then analyzed using logistic regression tests and presented as Odds Ratio. Subsequently, variables significantly correlated to Quality of Life were analyzed using determination and calibration tests. Statistical analysis was done using SPSS.

Results and Discussion

The sample size was 52.

The results of descriptive analysis are shown in Table 1 and 2.

Table 1. The Descriptive Analysis of Characteristic of Children with HIV/AIDS

Characteristic		Results	
		n	%
Sex	Male	28	53.8
	Female	24	46.2
Age	2-5 years old	9	17.3
	>5 years old	43	82.7
Address	Surabaya	8	15.4
	Outside Surabaya	44	84.6
PedsQL	Good	31	59.6
	Bad	21	40.4

Most of the subjects were male, more than 5 years old, lived outside Surabaya, and had good quality of life according to the PedsQL questionnaire. This study has the advantage of being able to find out

quickly how the quality of life of children with HIV / AIDS because it is done at one time, this study also focuses not only on children living in a big city such as Surabaya but several other cities such as Gresik, Trenggalek, and Probolinggo.

Table 2. Descriptive Analysis of Determinant Factors of Children with HIV/AIDS

Determinant factor		Results	
		n	%
Caretakers	Parents	29	55.8
	Not parents	23	44.2
Caretakers' education	Elementary school or not graduated	26	50
	Junior high school or higher	26	50
Caretakers' income	less than 1 million IDR	31	59.6
	1-5 million IDR	21	40.4
Caretakers' job	Housewife or unemployed	10	19.2
	Employed	42	80.8
First diagnosis	Less than 2 years ago	18	34.6
	More than 2 years ago	34	65.4
Duration between diagnosis and therapy	Less than 6 months	41	78.8
	More than 6 months	11	21.2
Immunodeficiency	None to mild	39	75
	Moderate to severe	13	25
Nutritional status	Good	31	59.6
	Bad	21	40.4
Stage when diagnosed	1-2	28	53.8
	3-4	24	46.2
Adherence to therapy	Good	38	73.1
	Bad	14	26.9
Medical care provider	Available	49	94.2
	Unavailable	3	5.8
Medical centers	Available	49	94.2
	Unavailable	3	5.8
Medical facilities and supplies	Available	49	94.2
	Unavailable	3	5.8
Opportunistic infection when diagnosed	Occurred	20	38.5
	Not occurred	32	61.5
ARV category	First line	50	96.2
	Second line	2	3.8

Most of the subjects were cared for by parents. Their caretakers were mostly employed and had under 1 million IDR per month. Most of them was first diagnosed more than 2 years ago and treated less than 6 months after being diagnosed, have none to mild immunodeficiency, good nutritional status, first diagnosed with stage 1-2, good adherence to therapy, access to medical care provider, medical center, facilities, and supplies, and get first line of ARV therapy. Most of them have no opportunistic infection when diagnosed.

The results of bivariate analysis using Chi Square are shown in Table 3. Variables correlated to the quality of life have p value less than 0.05.

Table 3. The Results of Bivariate Analysis between the Determinant Factors and Quality of Life of Children with HIV/AIDS

Determinant factor		PedsQL		P value	Odd ratio (CI 95%)
		Good	Bad	n	
Sex	Male	17 (54.8)	11 (52.3)	0.862	0.906 (0.298-2.751)
	Female	14 (45.1)	10 (47.6)		
Age	2-5 years old	1 (3.2)	8 (38)	0.001*	18.462 (2.090-164.046)
	>5 years old	30 (96.7)	13 (61.9)		
Domicile	Surabaya	6 (19.3)	2 (9.5)	0.335	2.280 (0.413-12.579)
	Outside Surabaya	25 (80.6)	19 (90.4)		
Caretakers	Parents	20 (64.5)	9 (42.8)	0.123	2.424 (0.779-7.542)
	Not parents	11 (35.4)	12 (57.1)		
Caretakers education	Elementary school or not graduated	13 (41.9)	13 (61.9)	0.158	2.250 (0.724-6.989)
	Junior high school or higher	18 (58)	8 (38)		
Caretakers income	less than 1 million IDR	14 (45.1)	17 (54.8)	0.010*	5,161 (1,408-18,912)
	1-5 million IDR	17 (54.8)	4 (45.1)		
Caretakers job	Housewife or unemployed	4 (12,9)	6 (28.5)	0.160	2.7 (0.657-11.102)
	Employed	27 (87)	15 (71.4)		

***Cont.*. Table 3. The Results of Bivariate Analysis between the Determinant Factors and Quality of Life of Children with HIV/AIDS**

First diagnosis	Less than 2 years ago	9 (29)	9 (42.8)	0.304	1.833 (0.574-5.855)
	More than 2 years ago	22 (70.9)	12 (57.1)		
Duration between diagnosis and therapy	Less than 6 months	29 (93.5)	12 (57.1)	0.002*	0.092
	More than 6 months	2 (6.4)	9 (42.8)		
Immuno-deficiency	None to mild	28 (90.3)	11 (25.3)	0.002*	0.118 (0.027-0.511)
	Moderate to severe	3 (9.6)	10 (47.6)		
Nutritional status	Good	23 (74.1)	8 (38)	0.009*	4.673 (1.1417-15.401)
	Bad	8 (25.8)	13 (61.9)		
Stage when diagnosed	1-2	19 (61,2)	9 (42.8)	0.191	0.474 (0.154-1.461)
	3-4	12 (38.7)	12 (57.1)		
Adherence to therapy	Good	27 (87)	11 (52.3)	0.006*	3.136 (1.583-23.789)
	Bad	4 (12.9)	10 (47.6)		
Medical care provider	Available	30 (96.7)	19(90.4)	0.339	3.158 (0.268-37.270)
	Unavailable	1 (3.2)	2 (9.5)		
Medical centers	Available	30 (96.7)	19(90.4)	0.339	3.158 (0.268-37.270)
	Unavailable	1 (3.2)	2 (9.5)		
Medical facilities and supplies	Available	30 (96.7)	19(90.4)	0.339	3.158 (0.268-37.270)
	Unavailable	1 (3.2)	2 (9.5)		
Opportunistic infection when diagnosed	Occurred	11 (35.4)	9 (42.8)	0.592	0.733 (0.236-2.282)
	Not occurred	20 (64.5)	12 (57.10)		
ARV category	First line	30 (96.7)	20 (95.2)	0.777	0.667
	Second line	1 (3.2)	1 (4.7)		

According to Chi-square test, age, monthly caregiver income, distance between diagnosis and therapy, immunological status, nutritional status and treatment adherence had a significant relationship with PedsQL. With the increase of nutritional status, a child's immunity will also increase, this can improve the health of children with HIV/AIDS both physically and mentally so that can improve their quality of life. This study uses the latest CD4/CD4% data and measurements of nutritional status were done at the time of sampling, so that we can find out the relationship of the patient's current immunological status and nutritional status with their current Quality of Life.

Those variables eventually underwent multivariate analysis using a logistic regression test. Multivariate analysis results are shown in Table 4.

Table 4. The Results of Multivariate Analysis between the Determinant Factors and Quality of Life of Children with HIV/AIDS

	Variable	B	P value	OR	CI	
					Upper limit	Lower limit
Step 1a	Age	3,048	0,042*	21,076	1,113	399,275
	Caretakers	0,706	0,466	2,027	0,303	13,555
	Caretakers' education	-0,628	0,498	0,534	0,087	3,276
	Caretakers' income	-1,469	0,138	0,230	0,033	1,600
	Caretakers' job	-0,951	0,439	0,386	0,035	4,288
	Duration between diagnosis and therapy	1,001	0,656	2,721	0,033	223,523
	Immunodeficiency	-0,283	0,890	0,753	0,013	42,200
	Nutritional status	0,841	0,336	2,319	0,418	12,865
	Stage when diagnosed	0,705	0,406	2,024	0,383	10,693
	Adherence to therapy	2,032	0,075*	7,632	0,816	71,403
	Constant	-3,536	0,089	0,029		
Step 8a	Age	2,933	0,014*	18,780	1,810	194,844
	Caretakers' income	-1,286	0,094	0,276	0,061	1,245
	Adherence to therapy	2,057	0,010*	7,823	1,631	37,516
	Constant	-2,741	0,053	0,065		

The result of multivariate analysis using a logistic regression test showed that age and patient's adherence to therapy plays a significant role. This research found that children aged more than 5 years old had 18 times better Quality of Life compared to 2-5 years old and children with good adherence to therapy had 8 times better Quality of Life than bad adherence to therapy. This result was similar to previous study held by Burack.[5]

Table 5. The Results of Determination and Calibration Test

Evaluation	Criteria	Results
Determination test	Nagelkerke R Squate test	47,1%
Calibration test	Hosmer-Lemeshow test	p = 0.884

Based on determination and calibration tests, both of those factors had influenced 47,1% towards the Quality of life of children with HIV/AIDS.

The majority of the study subjects were male and had a mean age of 8.2 ± 3.64 years. This is in accordance with the statistical description of new case finding of children with HIV/AIDS in Indonesia in 2020, where boys have a higher percentage than women (56.7% compared to 43.2%) with the majority aged less than 14 years.[6]

This research found that the older the age, the higher is the quality of life. This result was similar with research held in Africa which children aged more than 5 years old had better quality of life and no psychosocial problems.[7]

In a previous study, the independent variables in this research had been observed and correlated to the quality of life. A research found that the older the children, the better the quality of life and less psychosocial problem.[6] Parents play important role in life to improve the quality of life of children with HIV/AIDS.[8] Early diagnosis and ARV therapy has proven useful for prevention, clinical benefit, increases life expectancy, and reduces the incidence of HIV-related infections in the population.[9,10] Starting ARVs at a higher CD4 or CD4% can maximize the potential for immunological recovery.[10] Immunology and opportunistic infection also played role in the quality of life in pediatric HIV/AIDS.[11] According to a study, nutritional status was also significantly correlated with quality of life. Children with HIV/AIDS who experience malnutrition have an impact on poor quality of life.[12] Patient's adherence to therapy improves patient's condition and prevents infection, so that it improves the quality of life of children with HIV/AIDS.[13] Research by Bolton-Moore showed that proper medical center, medical care workers and medical facilities can provide good outcomes for children with HIV/AIDS.[14]

In this study, age and adherence to therapy has proven to have a role in a patient's quality of life. Children aged more than 5 years old were proven to have 18 times better Quality of Life compared to 2-5 years old. This may be due to the fact that by the age increasing, the level of adherence to treatment will increase so that in the end it can also improve the Quality of Life of children with HIV / AIDS. This result was in accordance with study held by Hidayat.[6]

Based on this research, children with good adherence to therapy had 8 times better Quality of Life than bad adherence to therapy. Adherence to therapy is a complex health behavior influenced by drug regimens, patient and family factors, and patient-medical personnel relationships.[13] The better the patient's adherence to therapy, the higher the success rate in therapy. Therefore, the quality of life of children with HIV/AIDS will improve. In contrast, bad adherence to therapy will cause side effects related to ARVs and immunological and viral complication, which will lead to a decrease in quality of life.[15]

Despite the results, this research still has some weaknesses. Bias may be caused by subjectivity due to the interview. Besides, this study has not excluded all chronic diseases so it is very likely that it can affect the quality of life. Last, this research was only conducted at one time so that the subjects were unable

to observe in a certain period.

Conclusion

Most children with HIV/AIDS who have received ARV therapy have a good quality of life. Age, monthly caregiver income, distance between diagnosis and therapy, immunological status, nutritional status and treatment adherence are significantly related to the Quality of Life of children with HIV/AIDS. Age and treatment adherence have the most significant relation with the Quality of Life of children with HIV/AIDS.

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References

1. Diyanayati K. *Permasalahan Penyandang HIV/AIDS*. J Penelit dan Pengemb Kesejaht Sos. 2006;**11**: 67–73. Available from: https://media.neliti.com/media/publications/52952-ID-permasalahan-penyandang-hivaids.pdf.
2. Irwanto I. *Kualitas Hidup Anak dengan HIV/AIDS: Manajemen HIV/AIDS Terkini, Komprehensif, Dan Multidisiplin.* Afif NH, Alfian NR, Cahyo WN, Tri PA, Azril OA, Arief B, Amin M, Nasronudin, editors. Surabaya: Airlangga University Press. 2019;745.
3. Vranda M, Mothi S. *Psychosocial issues of children infected with HIV/AIDS.* Indian J Psychol Med. 2013;**35**:19–22. Available from: https://doi.org/10.4103/0253- 7176.112195
4. Huriati. *HIV/AIDS pada Anak.* 2014;**9**:126–131.
5. Burack G, Gaur S, Rn RM, Petrova A. *Adherence to Antiretroviral Therapy in Pediatric Patients with Human Immunodeficiency Virus (HIV-1).* J Pediatr Nurs. 2010;**25**:500–504. Available from: https://doi.org/10.1016/j.pedn.2009.07.002
6. Hidayat MB. *Laporan Perkembangan HIV/AIDS & Penyakit Menular Seksual*, 2020.
7. Avabratha KS, Kodavanji B, Vaid J. *A Study of Psychosocial Problems in Families with HIV-Infected Children in Coastal Karnataka*. Genomic Med Biomarkers Heal Sci. 2011;**3**:72–75. Available from: https://doi.org/10.1016/j.gmbhs.2011.08.001
8. Lahai M, James PB, Nen N, Wurie HR, Conteh S. *A Cross-Sectional Study on Caregivers' Perspective of the Quality of Life and Adherence of Paediatric HIV Patients to Highly Active Antiretroviral Therapy*. BMC Pediatr. 2020;**20**:1–10.
9. Kementerian Kesehatan Republik Indonesia. *Pedoman Nasional Pelayanan Kedokteran Tatalaksana HIV*. Jakarta. 2019
10. Yin, Harrison LJ, Klein NJ, Lewis J, Melvin AJ, Tudor-Williams G Jr, REM. *Using CD4 Percentage and Age to Optimize Pediatric Antiretroviral Therapy Initiation*. Pediatrics. 2014;**134:**1104–1116.
11. Jadhav VM, Gabhale YR, Lala MM. *A Study of Clinical Spectrum of Opportunistic Infections in HIV Infected Children and Its Correlation with CD4*. Int J Contemp. Pediatr. 2019;**4:**1485–1490. Available from: https://doi.org/10.18203/2349-3291.ijcp20172691
12. Gopakumar KG, Bhat KG, Joseph N, Shetty AK. *Health-Related Quality of Life in Children with HIV Infection A Cross-Sectional Study from South India*. J Pediatr Infect Dis. 12, 2017;**12**:104–109. Available from: https://doi.org/10.1055/s-0037-1598181
13. Department of Health & Human Services of USA. *Guidelines for the Use of Antiretroviral*

Agents in Pediatric HIV Infection What's New in the Pediatric Guidelines. 2021. Available from: https://clinicalinfo.hiv.gov/sites/default/files/guidelines/documents/PediatricGuidelines.pdf

14. Bolton-Moore C, Cantrell RA, Chi BH, Sinkala M, Wilson CM, Wilfert C, Mwango A, Levy J, Abrams EJ. *Clinical Outcomes and CD4 Cell Response in Children Receiving Antiretroviral Therapy at Primary Health Care Facilities in Zambia*. J Am Med Assoc. 2007;**298**:1888–1899.
15. Mehta K, Heylen E, Shet A. *Adherence to Antiretroviral Therapy among Children Living with HIV in South India*. AIDS Behav. 2017**;20:**1076–1083. Available from: https://doi.org/10.1007/s10461-015-1207-7.