Are There Effects of Antiretroviral Usage, Caregiver Stigma, Caregiver Burden, and Caregiver Coping on the Quality of Life of Indonesian Children with HIV/AIDS?

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Abstract

Background

Antiretroviral (ARV) therapy has changed human immunodeficiency virus infections and acquired immune deficiency syndrome (HIV/AIDS) into chronic medical conditions. These conditions affect the quality of life of Indonesian children with HIV/AIDS. The aimed was analyzing the influence of ARV usage, caregiver stigma, caregiver burden, and caregiver coping on the quality of life of Indonesian children with HIV/AIDS.

Methods

Participants in this study were caregiver for Indonesian children with HIV/AIDS. This study measured ARV usage, caregiver stigma, caregiver burden, caregiver coping, and quality of life in Indonesian children with HIV/AIDS. Measurement data were analyzed using logistic regression test and ANOVA, test with $p < 0.05$.

Results

HIV/AIDS Indonesian children aged 7.7 ± 3.68 years, with an average participant age of 40.2 ± 11.26 years. Most participants were biological parents of Indonesian children with HIV/AIDS (64.2%) and female (56.6%). Participants stated that all Indonesian children with HIV/AIDS tend to keep their health status confidential. Most HIV/AIDS Indonesian children regularly used ARV (83.0%) and had a good quality of life (71.7%; $\beta = 0.683$; $p < 0.001$). Caregiver stigma value was 21.7 ± 2.06 , with a median value of 22 (15–26; $\beta = 0.064$; $p = 0.548$). Participants had moderate and mild caregiver burden, with percentage of 50.9% and 49.1%, respectively ($\beta = 0.058$; $p = 0.593$). Caregiver coping value was 77.2 ± 7.30 ($\beta = -0.196$; $p = 0.049$).

Conclusions

There is an influence of the use of ARV drugs and caregiver coping with the quality of life of Indonesian children with HIV/AIDS. Regular ARV use improves quality of life, while the higher the caregiver coping, the lower the quality of life.

Background

The Eastern Europe and Central Asia (EECA) region has an increasing number of epidemiology of patients with human immunodeficiency virus and acquired immune deficiency syndrome (HIV/AIDS) every year. It was estimated that around 760,000 adults and children lived with HIV/AIDS in EECA in 2000 and increased to 1.3 million [1]. In Indonesia, it was reported that in 2006–2010, there were 53 children with HIV/AIDS, of which 84.9% were HIV/AIDS positive parents [2]. Antiretroviral (ARV) therapy has

changed HIV/AIDS infection into a chronic medical condition, causing mortality rates to decline, resulting in an increase in the group of children infected with HIV / AIDS perinatal who grow into adulthood. The consequences of ARV usage include drug toxicity and medication adherence. However, problems that are often occurred in children and adolescents with HIV/AIDS include social stigmatization, low self-esteem, inhibiting sexual development, need for regular hospital visits, and repeated periods of school absence [3].

Indonesia is a developing country with 6,668 HIV cases and 16,964 AIDS patients including children [4]. East Java is a province with the second largest population in Indonesia, where Surabaya had the largest localization in Southeast Asia, which contributed to the number of children with HIV/AIDS. Recent study found that the number of HIV/AIDS cases in Indonesian children aged 0–4 years was 427 cases in East Java, Indonesia [5]. Based on the description above, researchers were interested in conducting research on the effect of ARV usage, caregiver stigma, caregiver burden, and caregiver coping on the quality of life in Indonesian children with HIV/AIDS in East Java, Indonesia.

Methods

Participants

The participants of this study were caregivers of Indonesian children with HIV/AIDS who met the participant criteria. Participant inclusion criteria included caregivers of Indonesian children with a diagnosis of HIV/AIDS [6,7], and aged 2-18 years. Participant exclusion criteria included caregivers with Indonesian children who were sick during data collection process, caregivers were unwilling to participate in the study, and caregivers or HIV/AIDS Indonesian children were not cooperative during data collection. Participants received an explanation regarding the rights and obligations during the study. In addition, the researchers explained the purpose and benefits of the research to the participant's family or guardian before the researchers asked for voluntary approval to become a participant in the study (informed consent).

Design

An analytical study with cross sectional design was conducted in the community of HIV/AIDS Indonesian children undergoing outpatient treatment at Dr. Soetomo General Academic Hospital, Surabaya, Indonesia, and the community of HIV/AIDS Indonesian children in Probolinggo, Indonesia. This community of HIV/AIDS Indonesian children has been formed, and the researchers used a total sample in this study. This research was conducted from July to December 2019. This research was conducted in East Java, Indonesia (Probolinggo City and Surabaya City). The number of participants in the study were 53 participants of Indonesian children with HIV/AIDS. This study confirmed the use of ARV drugs in Indonesian children with HIV/AIDS, measured caregiver stigma, caregiver burden, caregiver coping, and quality of life for Indonesian children with HIV/AIDS.

The caregiver stigma was assessed using a measured scale consisting of 9 items that measured perceived HIV stigma associated with people living with HIV/AIDS (PLWHA) and caregiver. The total score of stigma scale is in the range of 0-27, with a 4-point scale ranging from strongly disagree (0) to strongly agree (3). The Cronbach's alpha instrument value was 0.89 (PLWHA) and 0.92 (caregiver) [8,9].

Caregiver burden was assessed using Zarit Burden data instruments. This instrument consists of 22 items, which assess five main domains of stress burden, namely health, psychological well-being, financial, social life and patient relationships. The assessment is based on a 5-point Likert scale, from 0 = 'never' to 4 = 'almost always'. The final score ranges from 0 to 88, which is grouped into four categories: 0-20 (little or no burden), 21-40 (mild burden), 41-60 (moderate burden) and 61-88 (severe burden). Zarit Burden was declared valid and reliable with a Cronbach's alpha value of 0.93 [10,11].

Measurement of caregiver coping used a family crisis oriented personal evaluation scales (F-COPES) questionnaire. The instrument consists of 30-item questions designed to assess problem solving and coping strategies that families use when facing difficult situations. Caregiver assesses a series of coping techniques on 5 subscales namely: acquiring social support, seeking spiritual support, reframing, mobilizing family to acquire and accept help, and passive appraisal. Each subscale was assessed with 5 Likert points based on whether the family was involved in the technique [12]. F-COPES was declared valid and reliable with Cronbach's alpha = 0.89 [13].

Measurement of the quality of life of children with HIV/AIDS used a pediatric quality of life inventory (PedsQL), which is a questionnaire used to evaluate health-related quality of life (HRQOL) in children. PedsQL is a general health instrument consisting of 23 items that assess 5 health domains (physical function, emotional function, psychosocial function, social function, and school function) in children and adolescents aged 2 to 18. There are 23 questions that include physical functions (8 items), emotional functions (5 items), social functions (5 items), and school functions (5 items). The assessment of response of each question is based on a 5-point Likert scale: never (0), almost never (1), sometimes (2), often (3), almost always (4). Scores are transformed to a scale of 0-100 (0 = 100; 1 = 75; 2 = 50; 3 = 25; and 4 = 0). The total score of 23 items is the average of all answers. The value was good if ≥ 70 , and the instrument was valid and reliable with a Cronbach's alpha value > 0.7 [14-16].

Statistical Analysis

The statistical test used a multiple logistic regression test to obtain the effect of ARV drugs, caregiver stigma, caregiver burden, caregiver and caregiver coping on the quality of life of Indonesian children with HIV/AIDS. Statistical tests were significant if $p < 0.05$. In addition, this study employed Anova test to analyze the data.

Results

Characteristics of Participants

The average age of Indonesian children with HIV/AIDS was 7.7 ± 3.68 years, with a median value of 7 (3-18) years. Meanwhile, the average age of participants was 40.2 ± 11.26 years, with a median value of 38 (20-68) years. The average age of biological mother of HIV/AIDS Indonesian children was 33.8 ± 5.80 years, with a median value of 33 (23-48) years. The average age of biological father of HIV/AIDS Indonesian children was 35.6 ± 7.29 years, with a median value of 35 (24-63) years (Table 1). Most Indonesian children with HIV/AIDS in this study were male (54.7%), and most had elementary school education (49.1%) and kindergarten (32.1%). Most caregivers were biological parents of Indonesian children with HIV/AIDS (64.2%). Most caregivers were female as much as 56.6%. Most participants had elementary education (35.8%), followed by middle school (32.1%) and high school (28.3%). Most biological fathers of HIV/AIDS Indonesian children died (52.8%) and biological mothers of HIV/AIDS Indonesian children still live (56.6%). Participants stated that all HIV/AIDS Indonesian children tended to keep their health status confidential (Table 2).

Effects of Antiretroviral Use, Caregiver Stigma, Caregiver Burden and Caregiver Coping on the Quality of Life of Indonesian Children with HIV/AIDS

The quality of life of Indonesian children with HIV/AIDS in this study was generally good (71.7%). The quality of life value of Indonesian children with HIV/AIDS based on 4 subscales obtained the following results: good physical function (71.7%), good emotional function (73.6%), good social function (88.7%), and poor school function (52.8%). Most Indonesian children with HIV/AIDS used ARV regularly (83.0%; Table 2). This study found an influence of ARV usage on the quality of life of Indonesian children with HIV/AIDS ($\beta = 0.683$; $p < 0.001$), with value of each subscale as follows: physical function ($\beta = 0.644$; $p < 0.001$), emotional function ($\beta = 0.418$; $p = 0.001$), social function ($\beta = 0.468$; $p < 0.001$), and school function ($\beta = 0.369$; $p = 0.001$; Table 3). The results showed that effect of regular ARV use can improve the quality of life of Indonesian children with HIV/AIDS.

The caregiver stigma measurement obtained a value of 21.7 ± 2.06 , with a median value of 22 (15-26). There was no significant effect between caregiver stigma on the quality of life of Indonesian children with HIV/AIDS ($\beta = 0.064$; $p = 0.548$), with value of each subscale as follows: physical function ($\beta = 0.023$; $p = 0.845$), emotional function ($\beta = -0.066$; $p = 0.608$), social function ($\beta = 0.007$; $p = 0.957$), and school function ($\beta = 0.097$; $p = 0.418$). Measurement of caregiver burden obtained a moderate value of 50.9% and followed by mild category of 49.1%. There was no significant effect between caregiver burden on the quality of life of Indonesian children with HIV/AIDS ($\beta = 0.058$; $p = 0.593$), with value of each subscale as follows: physical function ($\beta = 0.044$; $p = 0.706$), emotional function ($\beta = 0.040$; $p = 0.769$), social function ($\beta = 0.151$; $p = 0.255$), and school function ($\beta = 0.113$; $p = 0.369$). The results showed that there is no influence of caregiver stigma and caregiver burden on the quality of life of Indonesian children with HIV/AIDS (Tables 2 & 3).

Measurement of caregiver coping obtained an average value of 77.2 ± 7.30 , with value of each subscale as follows: social support (13.3 ± 2.39), reframing (30.1 ± 4.30), spiritual support (14.2 ± 2.66), family mobilization (9.6 ± 3.21), and passive appraisal (11.1 ± 3.75). This study found an effect of caregiver coping on the quality of life of Indonesian children with HIV/AIDS ($\beta = -0.196$; $p = 0.049$), with value of each subscale as follows: physical function ($\beta = -0.074$; $p = 0.487$), emotional function ($\beta = -0.256$; $p = 0.042$), social function ($\beta = 0.002$; $p < 0.988$), and school function ($\beta = -0.410$; $p = 0.001$; table 3). These results indicated an influence of caregiver coping with the quality of life of Indonesian children with HIV/AIDS, in which the higher the value of caregiver coping, the lower the quality of life of Indonesian children with HIV/AIDS.

The highest score choices in each caregiver coping subscale from highest to lowest were reframing 3.8 ± 0.86 , spiritual support 3.5 ± 0.66 , passive appraisal 2.8 ± 0.93 , family mobilization 2.4 ± 0.80 , and social support 1.5 ± 0.27 (Figure 1). There was a significant comparison between each caregiver coping subscale, including reframing with family mobilization ($p < 0.001$), reframing with social support ($p < 0.001$), spiritual support with family mobilization ($p < 0.001$), spiritual support with social support ($p < 0.001$), passive appraisal with family mobilization ($p = 0.024$), and passive appraisal with social support ($p < 0.001$; Table 4).

Discussions

This study found that ARV drugs improves the quality of life of Indonesian children with HIV/AIDS, which is a condition consistent with some previous studies [17–19]. ARV therapy suppresses viral replication and reduces viral load in blood thereby boosting immune system [20], and has been shown to improve physical functioning of children with HIV/AIDS [21]. Regular consumption of ARVs helps the development of children with HIV/AIDS [22]. The use of ARV drugs makes this fatal disease (HIV/AIDS) manageable and reduces the occurrence of opportunistic infections [23].

In America, in 58 families with HIV/AIDS children, the reframing subscale occupied the highest-ranking choice followed by passive appraisal, spiritual support, family mobilization, and social support that rank lowest. Reframing describes the attitude of passive acceptance, reflecting tendency to overcome problems in family without seeking support from others such as friends, extended family or the community. This condition occurs as many families with HIV/AIDS children experience exclusion or rejection from the community. Passive appraisal occurs because families feel helpless about their ability to handle their child's medical problems, thus entrusting children's health problems to medical workers. Spiritual support is related to religious beliefs and activities. Many individuals with life-threatening illnesses attempt to deal with such events in a religious context. This requires collaboration with health workers, especially doctors, to combine understanding of spiritual beliefs with disease management to understand the problem of the illness experienced [24, 25].

Coping strategies used to solve problems vary, namely emotion-focused coping or passive coping and problem-focused coping or active coping. Reframing, spiritual support, and passive appraisal are part of

emotion-focused coping, while family mobilization and social support are part of problem-focused coping [13, 26]. Participants in this study had low scores on family mobilization and social support subscales, and tended to use emotion-focused coping. Emotion-focused coping is generally adopted when situations are considered uncontrolled and too difficult to handle and resolve [26]. This emotion-focused coping strategy is most often used by people living with HIV/AIDS to deal with the disease and its problems [25, 24, 27].

Social support subscale is rarely used by caregivers and HIV/AIDS patients. The condition is in accordance with the results of this study, in which caregivers keep their HIV/AIDS health status confidential. Improper coping strategies have a negative impact on physical and emotional conditions and reduce the quality of life of children with HIV/AIDS [24, 28]. This research found that caregiver's coping strategies are increasing, thus further reducing quality of life, especially on subscale of emotional function and school function in Indonesian children with HIV/AIDS. This arises because caregivers of HIV/AIDS children overprotect because of very high fears of being exposed to opportunistic infections, bullying, prejudice, discrimination, and future uncertainty of children due to their HIV status. Caregiver also keeps the child's HIV/AIDS status a secret and prevents them from cooperating in their care [27]. Overprotection causes children's dependence on caregivers, increasing children's emotional problems and negative behavior. These conditions cause risk of delay in children's development, social limitations, cognitive, language, and even neglect, so that it interferes with school activities, both interactions with friends and lessons [27, 29, 30]. Parents' feelings of guilt for reducing HIV/AIDS in children cause excessive total dedication, even routine and work they leave for the care and treatment of children [27, 30], consequently reducing family income, where the management of HIV/AIDS children is good for treatment and non-medical treatments such as schools require significant costs [27, 30, 29].

Individuals who deal with stress with problem-focused coping approach are reported to have a much better quality of life than those who adopt emotion-focused coping. Several studies have highlighted the importance of social support from various family and non-family elements as problem-focused coping in overcoming problems effectively, reducing stress and improving quality of life [25, 26]. In addition, the higher the social support, the higher the quality of life of HIV/AIDS patients [31].

Coping strategies used by HIV/AIDS child's caregivers appear to be important factors that need to be considered to improve health and quality of life of children with HIV/AIDS [27]. An intervention is needed that aims to help caregivers find and utilize appropriate and effective coping strategies [24] therefore clinicians must be sensitive to HIV/AIDS stigma and other specific factors that can disrupt various health support systems. Clinicians must also be ready to provide referrals to communities that are support physical and emotional health of HIV children to get various supports that improve family coping [25], thereby improving the quality of life of children with HIV/AIDS [31].

Conclusions

The use of ARV therapy reduces mortality and morbidity rate of HIV/AIDS children, but causes chronic conditions. Problems, such as social stigmatization, low self-esteem, impeded sexual development, the need for regular hospital visits, and repeated periods of school absence, are also occurred during the disease course. The number of Indonesian children with HIV/AIDS in East Java, Indonesia, is increasing and thus needs strategies for effective care. Caregiver is the closest person to Indonesian child with HIV/AIDS so their role must be maximized. Caregiver stigma and caregiver burden do not affect the quality of life of Indonesian children with HIV/AIDS. Meanwhile, regular use of ARV drugs has been proven to significantly improve the quality of life of Indonesia children with HIV/AIDS, where a more regular consumption of ARV drugs improves the quality of life of children. There is an influence of caregiver coping strategies on the quality of life of Indonesia children with HIV/AIDS. The more coping the caregiver, the lower the quality of life of Indonesia children with HIV/AIDS, because caregiver performs a more emotion-focused coping than problem-focused coping.

Abbreviations

EECA = Eastern Europe and Central Asia; HIV = human immunodeficiency virus; AIDS = acquired immune deficiency syndrome; ARV = Antiretroviral; PLWHA = people living with HIV/AIDS; F-COPES = family crisis oriented personal evaluation scales; PedsQL = pediatric quality of life inventory; HRQOL = health-related quality of life.

Declarations

Conflict of Interest

Azwin Mengindra Putera, Irwanto and Margarita Maria Maramis declare that they have no conflict of interest.

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None.

Author's Contribution

All authors contributed toward data analysis, drafting and revising the paper, gave final approval of the version to be published and agree to be accountable for all aspects of the work.

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Ethical Approval

This research had been conducted ethical approval at the Ethics Committee Dr. Soetomo General Academic Hospital, Surabaya, Indonesia and declared eligible to be implemented (1290/KEPK/VII/2019). Participants received an explanation related to their rights and obligations during the study. Participants were required to fill out an informed consent sheet voluntarily.

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Tables

Table 1. Characteristics of Participants

Characteristics	n (53)
Child’s age	7.7 ± 3.68
Caregiver’s age	40.2 ± 11.26
Caregiver stigma	21.7 ± 2.06
Caregiver coping	
Total	77.2 ± 7.30
Social support	13.3 ± 2.39
Reframing	30.1 ± 4.30
Spiritual support	14.2 ± 2.66
Family mobilization	9.6 ± 3.21
Passive appraisal	11.1 ± 3.75

Table 2. Characteristics of Participant’s Frequency Distribution

Characteristics	n (53)
Child's sex	
Male	29 (54.7)
Female	24 (45.3)
Child's education	
Not attending school	3 (5.7)
Kindergarten	17 (32.1)
Elementary school	26 (49.1)
Junior high school	5 (9.4)
Senior high school	2 (3.8)
Biological father	
Live	22 (41.5)
Die	28 (52.8)
Unknown	3 (5.7)
Biological mother	
Live	30 (56.6)
Die	22 (41.5)
Unknown	1 (1.9)
Caregiver	
Biological parents	34 (64.2)
Others	19 (35.8)
Caregiver's sex	
Male	23 (43.4)
Female	30 (56.6)
Caregiver's education	
Elementary school	19 (35.8)
Junior high school	17 (32.1)
Senior high school	15 (28.3)
College	2 (3.8)
Caregiver's income	
High	13 (24.5)
Low	40 (75.5)
Caregiver's burden	
None	0 (0.0)
Mild	26 (49.1)
Moderate	27 (50.9)
Heavy	0 (0.0)
Quality of life of children with HIV/AIDS	
Total	
≥ 70	38 (71.7)
< 70	15 (28.3)
Physical function	
≥ 70	38 (71.7)
< 70	15 (28.3)
Emotional function	
≥ 70	39 (73.6)
< 70	14 (26.4)
Social function	
≥ 70	47 (88.7)
< 70	6 (11.3)

School function	
≥ 70	25 (47.2)
< 70	28 (52.8)
ARV usage	
Regular	44 (83.0)
Irregular	9 (17.0)
Status of children with HIV/AIDS	
Confidential	53 (100.0)
No	0 (0.0)

Table 3. Effects of Antiretroviral Use, Caregiver Stigma, Caregiver Burden, and Caregiver Coping on the Quality of Life of Indonesia Children with HIV / AIDS

Quality of Life	ARV		Caregiver Stigma		Caregiver Burden		Caregiver Coping	
	β	p	β	p	β	p	β	p
Total	0.683	0.000**	0.064	0.548	0.058	0.593	-0.196	0.049
Physical function	0.644	0.000**	0.023	0.845	0.044	0.706	-0.076	0.487
Emotional function	0.418	0.001*	-0.066	0.608	0.040	0.769	-0.256	0.042
Social function	0.468	0.000**	0.007	0.957	0.151	0.255	0.002	0.988
School function	0.397	0.001*	0.097	0.418	0.113	0.369	-0.410	0.001

ARV=antiretroviral; *significant < 0.05; **significant <0.001

Table 4. Comparison of Caregiver Coping Subscale between Emotion-Focused Coping and Problem-Focused Coping

Caregiver Coping	Emotion-Focused Coping		
Problem-focused coping	Reframing	Spiritual support	Passive appraisal
Family mobilization	0.000**	0.000**	0.024*
Social support	0.000**	0.000**	0.000**

*significant < 0.05; **significant <0.001

Figures

Figure 1

The highest score choices in each caregiver coping subscale from highest to lowest were reframing 3.8 ± 0.86 , spiritual support 3.5 ± 0.66 , passive appraisal 2.8 ± 0.93 , family mobilization 2.4 ± 0.80 , and social support 1.5 ± 0.27 .