PARENTS ANXIETIES IN CARING FOR CHILDREN WITH HIV / AIDS

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Abstract

This study examines the parents' anxiety in parenting children with HIV/AIDS at Yayasan Pelita Ilmu Jakarta. The purpose of this study to obtain an empirical description of the characteristics of respondents and the physical condition related anxiety. The method used in this research is quantitative approach. The sample size of this research is 30 people taken by cluster sampling technique. Data collection techniques used were questionnaires and documentation studies. The results show that parents who have children with HIV/AIDS experience anxiety in parenting. Respondents have severe anxiety on physical aspect equal to 53,33%, This anxiety is most dominantly triggered by fears of stigma and discrimination, as well as the health conditions of children with HIV / AIDS which are vulnerable. The results of the research problem analysis require problem-solving efforts so that researchers propose an anxiety program reduction for parents of children with HIV/AIDS. This program aims to improve the parents' skills in dealing with situations that could be trigger their anxiety.

Keywords:

Anxiety, Parents, Parenting, Children With HIV/AIDS

INTRODUCTION

IV / AIDS transmission can occur at any age group, including children. Data from the Indonesian Ministry of Health reported that there were 1,409 cases of children with HIV / AIDS aged 0-4 years (Kementrian Kesehatan, 2014). It is likely that the number will increase, this is because cases of HIV / AIDS are an "iceberg" phenomenon that is what appears on the surface is only a fraction of the total facts.

According to the Convention on the Rights of the Child (KHA), children with HIV / AIDS are in the category of "children in need special protection" or children need special protection. This special form of protection for children with HIV / AIDS is in the form of supervision, prevention, treatment, care and rehabilitation. These tasks are components of the parenting task that must be fulfilled by a caregiver, namely the parent.

Care for children with HIV / AIDS has several specificities that must be considered, especially in terms of children's health. Things that need to be considered in terms of children's health are complete immunization for children, maintaining the intake of foods rich in energy and containing micronutrients, maintaining a healthy lifestyle, taking ARVs on time, giving the right dose of medicine, seeing the doctor immediately when the child is sick. . (Poindexter, 2010; Brinkhoft, MWG & Boule, A., Weigel, R, Marthers, C. 2009).

Another issue related to children with HIV is such as the issue of HIV in society where there is still stigma so that from a social perspective, children with HIV / AIDS are prone to problems of discrimination. Stigma and discrimination can be a source of anxiety for parents. The process of implementing care for children with HIV / AIDS will be greatly influenced by the experience and knowledge of parents.

Based on the student practicum report at the Pelita Ilmu Foundation, there are seven out of ten parents who have HIV positive children in South Jakarta. Where they choose to have closed status, that is, they do not disclose their HIV positive status to their extended family and community. However, some of these parents chose open status to their extended family, but not to the community. Parents who have HIV-positive children express concerns about the risk of discriminatory treatment if other people know their status (Juariah, 2016). This worry is part of anxiety. Craig (2009) states that anxiety is a feeling of uneasiness, worry, or fear of something that is unclear or unknown. Parents who have HIV-positive children also have concerns about issues of stigma, discrimination and also the child's health condition and the child's future.

Meanwhile, children with HIV / AIDS need parental care that is more comprehensive than other children in general because HIV sufferers face physical, psychological, social and spiritual health problems (Poindexter, 2010; Ellya Susilowati, 2010)

This condition gets worse if parents also lack knowledge and attitudes to face HIV & AIDS which results in less effective care (Amalia, 2013). Meanwhile, a disease and its consequences, whether due to illness or certain medical interventions, can cause negative feelings such as anxiety, depression, anger, or feelings of helplessness and negative feelings. And the condition of the sick child will also affect the child's parents' anxiety (Safarino, 2006)

The aspects of anxiety according to Nevid (2005) divides the aspects of anxiety into three aspects, namely, physical, cognitive, and behavioral aspects. In connection with this problem, how to research it

Currently, the government has begun to pay more attention to protecting children infected with HIV / AIDS. This is shown by the passing of Law Number 35 of 2014 concerning Amendments to Law Number 23 of 2002 concerning Child Protection. Through this law, children with HIV / AIDS are guaranteed better legal protection than before. The presence of a social service organization concerned with HIV / AIDS is a concrete implementation of the protection of children with HIV / AIDS. One such organization is the Pellita Ilmu Jakarta Foundation. While

The problem in this research is how anxious parents are in caring for children with HIV / AIDS at the Pelita Ilmu Jakarta Foundation. These problems are detailed into subproblematics as follows: 1) What are the characteristics of the respondents; and 2) What is the physical condition of the respondent who experiences anxiety

RESEARCH METHOD

This research uses a quantitative approach with the census method. The use of a quantitative approach is considered appropriate because the purpose of this study is to test a theory and produce general or broad conclusions.

The population of this study was 80 parents who have children and care for children with HIV / AIDS in DKI Jakarta and received the Mitigation Program from the Pelita Ilmu Jakarta Foundation. The number of samples studied was 30 people. Sampling was carried out by cluster sampling, namely the division of clusters was carried out based on administrative areas, namely Central Jakarta, North Jakarta, South Jakarta, East Jakarta, and West Jakarta.

The data collection technique was carried out by means of a questionnaire that contained statements showing biological, behavioral and cognitive anxiety symptoms experienced by parents in caring for children with HIV / AIDS. In addition, a documentary study was also carried out by reviewing various supporting documents available in the field to complement information about parental anxiety in caring for children with HIV / AIDS (Ariskunto, 2006).

The measurement of parental anxiety uses a rating scale which contains statements based on the theory of anxiety and parenting of children with HIV / AIDS. The measuring instrument contains statements of anxiety symptoms which are weighted with a number between 0-4. No symptoms are coded with the number 0, mild symptoms are coded with number 1, moderate symptoms are coded with number 3, and very severe symptoms are coded with digit 4.

This measuring tool uses ordinal data because each answer shows a different level from one another. Ordinal measurement level is used to sort objects from lowest to highest, or vice versa.

RESULT

This research was conducted at the Pelita Ilmu Foundation (YPI) Jakarta where this foundation runs a service program for people living with HIV / AIDS (PLWHA), children with HIV / AIDS (ADHA), parents who have ADHA, teenagers, teachers, high risk groups (Resti), and society at large. The resti here are men who have sex with men (MSM), transgender women, heterosexuals, prostitutes, and drug needle users..

1. Characteristics of respondents

Those who became respondents in this study were between 20 to 62 years old. Most (36.67%) were 27-33 years old, and 27% were female; 24% are biological parents, however, there are 6 guardians who care for ADHA. The

age of the ADHA in care ranged from 1 to 16 years. In detail, the packaging age is as in the following table:

Table 1
ADHA Characteristics Based on Age Who is in the Care of Respondents

No.	Age (Year)	Freq	Percentage (%)
1.	1 - 3	7	23,33
2.	4 - 6	5	16,67
3.	7 - 9	5	16,67
4.	10 - 12	10	33,33
5.	13 - 16	3	10,00
Amount		30	100,00

From the table above, it can be seen that most (33.33%) children are aged 10-12 years, and there are 1 to 3 years as many as 23.33%. And from the gender of children as much as 70% are girls, and 30% are boys.

1. Parents' Anxiety

The aspects of anxiety that are measured in this paper are seen from the physical point of view 1) difficulty sleeping when thinking about children's educational needs; 2) Heart palpitations when thinking about the need for nutrition, vitamins and milk; 3) Restless if there are problems with eating patterns; 4) nervous and restless when thinking about the child's height growth; 5) not calm when thinking about children's cognitive development; 6) not calm when thinking about the social environment; 7) Trembling at the thought of HIV status; 8) The body sweats when thinking about ADHA being stigmatized and experiencing discriminatory actions; 9) Feeling restless when ADHA is difficult to get along with 10) Trembling when thinking about the HIV status of children being known to others; 11) Body Sweats When Thinking ADHA Is Getting Stigma; 12) Headache When ADHA Gets Hospital Treatment; 13) It's hard to sleep when ADHA falls ill; 14) Easy to cry if ADHA experiences withdrawal of medicine: 15: Feeling restless if ADHA does not adhere to taking medication: 15) lack of sleep if ADHA feels side effects due to not being suitable for drugs; 16) Heart palpitations when the ADHA CD4 count is low.

Based on the results of these measurements, the cumulative total score is calculated using the maximum and minimum total score calculations as follows:

1) Calculate the maximum and minimum total scores

Total score = Score the
Maximum = highest ×
∑ Max = Total
∑ Max question
5 × 20
100

Total score = score the
minimum = lowest ×
∑ Min = total
∑ Min question
1 × 20
20

2) Calculating class intervals

Interval classes here are defined based on 4 categories of anxiety levels, namely mild, moderate, severe, and very heavy. So to find the class interval is the range divided by the number of interval classes, which is 4. The following is the calculation.

Interval = (∑Max -
class = ∑Min) : 4
c = (100-20) : 4
c = 80 : 4
c 20

Based on this calculation, it can be determined that the range of the interval class is 20. Furthermore, the calculated class range of 20 is used to determine the value of the interval which can indicate the level of physical anxiety in the respondent. Class interval value determination refers back to the minimum and maximum values, as well as the interval class. This determination resulted in the class interval values, namely 20-39 being light, 40-59 being moderate, 60-79 being heavy, and 80-100 being very heavy. Then these results are interpreted nto data analysis into categories.

Data analysis at this calculation stage is by giving categories to each respondent's answer score. This category adjusts between the respondent's answer score and the class interval value in each category. After that, each category was grouped and its frequency was calculated. The results of the interpretation of the data analysis can be seen in Table 2 below.

Tabel 2 Level Interval Measurement Category

Category	Interval	Freq	percentage
Light	20 - 40	3	10,00
Moderate	41- 60	5	16,67
Weight	61- 80	16	53,33
Very heavy	81- 100	6	20,00
Total		30	100,00

Based on the contents of Table 2, it can be seen that the largest value shows that the majority of respondents have a severe level of physical anxiety, which is 16 people or 53.33%. The data can be re-analyzed by calculating the mode and median to see how the respondent's physical anxiety is in terms of the mean data. However, before calculating the mode and median, it is necessary to determine the class and the lower edge of the class (b), that is, the interval class with the greatest frequency. Furthermore, to get the mode and median values, the calculations are as follows.

a) Calculating and assigning the mode values

Based on these calculations, the mode or score of respondents' anxiety that often arises is 70.This means that in the category of severe anxiety, the respondent's score is 70.

b) Calculating and determining the median value.

$$\text{Modus (Mo)} = b + r\left(\frac{16-5}{(16-5)+(16-6)}\right)$$

$$\text{Mo} = 60{,}5 + 20\ (0{,}52)$$

$$\text{Mo} = 60{,}5 + 10{,}4$$

$$\text{Mo} = 70{,}09 \sim 70$$

$$\text{Median (Md)} = b + r\left(\frac{{}^{1}/_{2}n - \sum F}{f\ Median}\right)$$

$$\text{Mo} = 60{,}5 + 20\left(\frac{15-8}{16}\right)$$

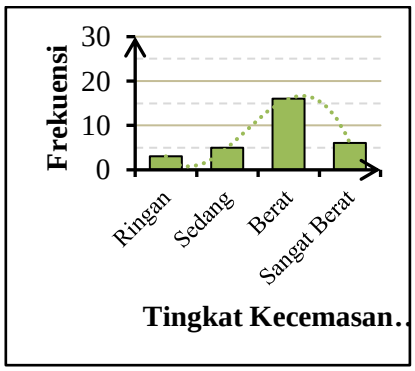
$$\text{Mo} = 60{,}5 + 8{,}8$$

$$\text{Mo} = 69{,}3 \sim 69$$

Based on these calculations, the median or mean value of all respondents' anxiety scores is 69. This means that in the category of severe anxiety it has an average location of 69.

Furthermore, these results can be described in Figure 1 below.

Figure 1 Concerning the Level of Anxiety of Parents against Children with HIV



Based on Figure 41.1, it can be seen that the highest score graph is in the severe anxiety category. There is a difference between the number of respondents who experience severe anxiety and the number of respondents who experience mild anxiety, namely 13 people. The graph in the figure also shows a bell-shaped curve, which means that the data in this study are normally distributed.

The graph in Figure 1 can also provide an overall picture of the respondent's physical anxiety is severe, regardless of what variables affect it. However, anxiety disorders are inherently individual. This means that anxiety can be felt differently in each respondent, for example on the respondent's physicality.

For example, one respondent felt severe anxiety on symptoms of insomnia, while another respondent felt severe anxiety on symptoms of anxiety. On the one hand, one respondent could feel severe anxiety in both symptoms. This difference will create a difference in the number of answers so that the level of anxiety will be individual. However, when viewed as a whole, the respondents have severe anxiety about the physical symptoms being studied. This severe anxiety is characterized by the appearance of symptoms of anxiety with frequent intensity and lasts quite a long time at the time of the anxiety.

DISCUSSION

From the research findings, the level of parental acuity in caring for children with HIV can be analyzed as follows:

1. **The condition of families and children with HIV / AIDS**

   Most of those who became ADHA parents (46.67%) were between 27 and 40 years old. Referring to Hurlock's theory of the stages of human development, the majority of respondents fall into the early adulthood category, namely 18-40 years old. At this time a person undergoes a process of adjustment in fulfilling roles and responsibilities for family and work. And, 90 percent of those who become parents are female. This shows that women or mothers are more dominant in caring for ADHA on a daily basis. However, the results of the study found that 20% were guardians. Those who become guardians are their extended family, namely their grandmother, aunt and aunt. This is consistent with alternative care as stated by Petr (2004). One of the causes of ADHA's loss of parents is death due to HIV / AIDS and parental divorce.

   Most of the children in care (47%) were between 1 to 6 years old. This shows that children still need intensive care to support children's development.

2. **Parents' anxiety in parenting**

Anxiety can be felt by anyone from children to adults. This anxiety is a form of reaction to defend themselves from something that is considered to be personal threat. Nevid (2005) explains that anxiety is an emotional state characterized by physiological arousal, unpleasant tense feelings, and a comprehensive feeling that something bad will happen. Anxiety is also a normal thing that happens to every individual, unless it occurs in excess.

As with other psychological disorders, excessive anxiety disorder will also cause obstacles in carrying out one's role and status. The triggers for the emergence of anxiety disorders in each person are different, including how the level of anxiety reactions in a person is.

The results showed that the level of parental anxiety in caring for ADHA was in the heavy category.

a. Anxiety faces health problems

The results showed that parental anxiety was categorized as severe at several points related to children's health, namely: (1) Thinking about the child's diet; (2) slow growth of children; (3) experiencing continuous weight loss; (4) ADHA cognitive development is slow.

The level of parental anxiety is related to health when ADHA weight drops, headaches when ADHA is sick, restless and easy to cry when ADHA withdraws from medication, sleep is not calm, and heart palpitations when ADHA CD4 is low. The emergence of concern is also caused by negative thoughts in parents that cannot be handled, especially regarding matters relating to ADHA health. Physical anxiety shown by parents is feeling restless, nervous, feeling uneasy, trembling, and sweaty bodies facing some of the child's problems

Several references suggest that the physical condition of ADHA is five times lower than that of normal children, as well as lower life expectancy (Muhaemin et al, 2010). This condition requires attention from parents, while caring for a child with HIV / AIDS requires parental strength.

b. Anxiety faces stigma, discrimination and HIV positive status

The results showed that parents experienced a high level of anxiety on aspects related to stigma, HIV status and discrimination. HIV stigma and discrimination are psychological problems of people with HIV, this also applies to ADHA. Pardasani, Moreno, Forge in Poindexter (2010) suggest that the stigma experienced by someone with HIV / AIDS is fear, anxiety, shame, deprivation of rights, hostility, exclusion, and threats to survival. This condition will worsen the condition of the child's parents in carrying out child care.

Catz and Kelly (2001; Nevid, 2005) suggest that people with HIV, although not all, experience psychological problems, especially anxiety and depression. This condition also affects the child's parents. Parents' concern may be caused by negative thoughts in respondents that cannot be handled, especially regarding matters relating to ADHA health. Parents also do not understand about anxiety management. Based on the results of this analysis, several respondents 'needs are needed that need to be met so that respondents' anxiety can be handled.

a. Anxiety management knowledge

One of the needs in an effort to deal with anxiety is to increase knowledge about anxiety and stress. Nevid (2005) states that handling psychological disorders (anxiety) can use training in stress management techniques. To do this, parents need to be given mature reinforcement from an expert in their field. This reinforcement is in the form of proper knowledge and practice in dealing with anxiety. Increasing anxiety management skills will directly support the optimal ADHA parenting process.

b. Anxiety management skills

Anxiety must be managed properly so that it is controlled and does not cause suffering. Lutgendorf (Nevid, 2005) states that coping skills training and cognitive-behavioral therapy have been shown to improve psychological function and the ability to handle stress in PLWHA, including reducing anxiety and depression. Therapists can help parents deal with anxiety through several activities that are filled with therapy. Some therapies are very useful for reducing anxiety levels in a person, such as self-relaxation and cognitive-behavioral therapy.

Barlow (1998; Nevid, 2005) said that in a controlled study cognitive-behavioral therapy produced greater benefits than other controlled conditions or alternative therapies. This therapy is a part of anxiety management that helps reduce respondents' anxiety, as well as provides anxiety therapy skills that can be applied on their own.

CONCLUSION

Children with HIV / AIDS have the right to optimal care. Parents are also responsible for providing care so that it can encourage child development. However, the results showed that parents have, so it is suggested to increase the capacity of parents to do stress management.

REFERENCES

Achmat Zakarija dan Amelia Pramono. 2015. *Jurnal Perempuan Dan Anak Vol. 1 No.1: Intervensi Care Support Treatment Bersasaran Anak dengan HIV/AIDS*. file:///D:/ASUSbackup/pdf%20doc/asuhanAdha.pdf. Diakses pada 26 Juni 2016.

Amalia A'immatul A. dan Rachmat Hargono. 2013. *Jurnal Promkes Vol.1 No.1: Dampak Pola Asuh Terhadap Perkembangan Emosional Anak Dengan HIV/AIDS*. file:///D:/ASUSbackup/pdf%20doc/ipi90314.pdf. Diakses pada 16 September 2015.

Aziza, A. A. A. I., & Hargono, R. (2013). Impact On Growth Patterns Of Emotional Asuh Child Hiv & Aids. *Jurnal Promkes, 1*(01)

Brinkhoft, MWG & Boule, A., Weigel, R, Marthers, C. (2009**).** Mortality of HIV - infected patient starting antireroviral therapy in sub Sahara Africa : comparison with HIV-unrelated mortality, *Plos Med,* 6 (4): 1371

Craig, G. (2009). *Kesehatan mental*. Jakarta: Penerbit Buku Kedokteran EGC.

Deswanti, A. D., & Imelda, J. D. (2016). Proses Disclosure Dan Kondisi Psikososial Anak Dengan Hiv/Aids. *Journal Of Social Welfare*, *17*(2).

Davison, Gerald C., John Neale, dan Ann Kring. 2006. *Psikologi Abnormal*. Jakarta: CV. Rajawali Press

Ernawati, E., & Armiyati, Y. (2014). Analisis Kebutuhan Perawatan Di Rumah Untuk Penderita Hiv/Aids Anak. In *ProsiD*

Muhaimin, T., Utomo, B., Utoyo, D. B., Kurniati, N., Anugrahini, T., Utami, F. R., & Zuliatie, E. (2011). Instrumen Pengukuran Kualitas Hidup Anak Terinfeksi HIV. *Kesmas: National Public Health Journal*, *6*(3), 126-132.

Neuman, Lawrence. (2006). *Social research methods. Qualitative and quantitative approaches.* United State of America: Pearson International Edition.

Nurhayati, G. E., Murwasuminar, B. J., & Manap, A. (2018). Hambatan Dan Tantangan Orang Tua (Ibu) Pada Saat Melakukan Perawatan Anak Dengan HIV/AIDS (Adha) Yang Mengakses Layanan HIV di Kota Bandung. *Sehat Masada*, *12*(2), 123-143.

Poindexter, Chynthia Canon. 2010. Handbook of HIV and social work: principle, practice, and population. New Jersey: John Wiley & Soni, Inc.

Sarafino, E. P. (2006). *Health Psychology : Biopsychosocial Interactions*. Fifth Edition. USA : John Wiley & Sons.

Siswanto, F. K. (2017). Implementasi Perlindungan Hak Anak Pengidap Penyakit Hiv/Aids. *Perspektif Hukum*, *15*(2), 238-250.

Susilowati, E. (2013). *Wanita yang mempunyai HIV/AIDS dan pasangan suami yang menyuntik dadah di Bandung, Indonesia*(Doctoral dissertation, Universiti Sains Malaysia).

Juariah Marwah Dhikiah (2016), Laporan Praktikum. Sekolah Tinggi Kesejahteraan Sosial Bandung.

Wood, M. E. (2002). *Ecotourism: principles,*

practices and policies for sustainability. UNEP. Artikel dalam http://www.unepie.org/tourism/library/ecotourism.htm. Diunduh 19 Maret 2013.

Lee GM, Gortmaker SL, McIntosh K, Huges MD, Oleske JM. Quality of life of children and adolescent: impact of HIV infection and anti- retroviral treatment. Pediatrics. 2006; 117: 273-83.

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