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Quality of Life of Children with Congenital Adrenal Hyperplasia After Covid-19 Pandemic at Dr. Soetomo Hospital Surabaya

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ABSTRACT

Background: Congenital adrenal hyperplasia (CAH) is a recessive autosomal disease that affects the synthesis of steroid hormones in the adrenal cortex. Patients with CAH usually have their quality of life affected by symptoms of increased androgens and virilization, the mental burden of daily drug consumption, and anxiety about adrenal crisis. In addition, the COVID-19 pandemic will also affect the quality of life of CAH children. ***Objective:*** The aim of the study was to determine the demographic data and quality of life of CAH children after the COVID-19 pandemic at Dr. Soetomo Hospital, Surabaya. ***Method:*** This study is descriptive research because it only describes the quality of life of CAH children after the COVID-19 pandemic at Dr. Soetomo Hospital, Surabaya. The design used is Cross Sectional which emphasizes the measurement time at one time. The sample of this study is children to adolescents aged 2-18 years who were diagnosed with congenital adrenal hyperplasia at Dr. Soetomo Hospital, Surabaya. This study uses primary data obtained from filling out the results of the PedsQL version 4.0 questionnaire through Google Forms. ***Result:*** The results of the study were obtained from 21 samples who were willing to fill out the questionnaire and 20 samples that were in accordance with the inclusion criteria. The study sample consisted of toddlers (age 2-4 years, n = 6), young children (age 5-7 years, n = 7), children (age 8-12 years, n = 6), and adolescents (age 13-18 years, n = 1). CAH children are dominated by 13 (65%) women. The education of CAH children is the most at the kindergarten level. The education of parents of CAH children is the highest high school level and the highest socioeconomic level is the middle level (1.2 million – 6 million). ***Conclusion:*** The quality of life of children with congenital adrenal hyperplasia after the COVID-19 pandemic at Dr. Soetomo Hospital, Surabaya namely the age group of 2-4 years has a total score of 75.6, the age group of 5-7 years has a total score of 76.62 (child report) and 78.42 (parent report), the age group of 8-12 years has a total score of 78.62 (child report) and 76.63 (parent report), and the age group of 13-18 years has a total score of 80.43 (child report) and 82.61 (parent report).

Keywords: congenital adrenal hyperplasia; quality of life; PedsQL version 4.0.

INTRODUCTION

Congenital adrenal hyperplasia (CAH) is a recessive autosomal disease that affects the synthesis of steroid hormones in the adrenal cortex [1]. Child CAH is usually affected by symptoms of increased androgens and virilization, the burden of the mind of taking medication every day because it is a chronic disease, and anxiety about the adrenal crisis [2]. Some studies mention that an increase in pain duration in chronic diseases such as diabetes is linked with a decrease in the patient's quality of life [3].

Neonatal screening data globally from 13 countries (America, France, Brazil, New Zealand, Japan, United Kingdom, Italy, Switzerland, Portugal, Germany, Sweden, Canada, and Spain) stated that out of 6.5 million newborns, 1 in 15,000 infants have CAH [4]. Research data in New York stated that about 2 million babies were detected with an increase in 17-OHP. After 10,574 infants were re-screened, 105 infants were diagnosed with CAH [5]. Data on the prevalence of CAH children in Indonesia is still not available, but UKK IDAI Pediatric Endocrinology recorded that nearly 400 children were diagnosed with CAH [6]. CAH children experience physical and psychosocial consequences that are significant [7]. This statement is in line with the opinion of Rochmah and her friends that CAH can affect the social problems of affected children, for example, some children feel ashamed and even consider their illness a disgrace.

These factors will affect the quality of life of children with CAH. On the other hand, health facilities for children with CAH in Indonesia and developing countries are also still limited [8]. Many studies state that CAH children also have an impact on the psychosocial impact of the parents who care for them [9]. A study by Zainuddin and his friend stated that parents of CAH children have a greater negative perception than parents of children with other chronic diseases such as diabetes mellitus. They are worried about genital surgery, virilization symptoms, and the fertility of their children [10].

During the COVID-19 pandemic, the transportation of patients to Dr. Soetomo Hospital for treatment was disrupted due to the lockdown policy. Patients and their families are afraid of contracting COVID-19 because Dr. Soetomo Hospital is one of the hospitals that are referred for COVID-19 patients. In addition, socioeconomic conditions also affect patients to go to the hospital for control. These factors will have an impact on the quality of life of children with CAH [8]. There are several challenges in the management of CAH in developing countries such as screening kits and hormonal test kits that are not available in some developing countries, which causes delays in diagnosis. In addition, the drugs used are very difficult to obtain because they are only available on the black market [11]. Until now, there is no data on the quality of life of CAH children at Dr. Soetomo Hospital after the COVID-19 pandemic. Therefore, this study aims to determine the quality of life of CAH children at Dr. Soetomo Hospital Surabaya after the COVID-19 pandemic and it is hoped that the results of this study can bring benefits and can be used as a source of information.

METHOD

This study is descriptive research because it only describes the quality of life of CAH children after the COVID-19 pandemic at Dr. Soetomo Hospital, Surabaya. The design used is Cross Sectional which emphasizes the measurement time at one time. The sample of this study is children to adolescents aged 2-18 years who were diagnosed with congenital adrenal hyperplasia at Dr. Soetomo Hospital, Surabaya. This study uses primary data obtained from filling out the results of the PedsQL version 4.0 questionnaire through Google Forms. PedsQL will be translated into Indonesian (using the services of a certified English translator). Purnamawati and her friends have conducted a validity and reliability test of the Indonesian version of PedsQL 4.0 and the results of the instrument are valid and reliable for measuring the quality of life of children with chronic diseases such as Chronic Kidney Disease (CKD) [12]. PedsQL version 4.0 consists of 23 questionnaire items, a Physical Health Summary score equivalent to physical function (8 items), and a Psychosocial Health Summary score (emotional function [5 items], social function [5 items], and school function [5 items]). PedsQL also has a child and parent report form because it has a different perspective on the impact of congenital adrenal hyperplasia on quality of life.

RESULT AND DISCUSSION

The basic characteristics of the patient are shown in Table 1. Data was obtained from as many as 21 Patients who were willing to fill out the questionnaire and who entered the inclusion criteria 20 patients. One patient did not enter the inclusion criteria because he was under 2 years old. The diagnosis of CAH in subjects was established based on elevated 17-OHP levels. Based on Table 5.1, it can be seen that CAH patients are dominated by women, namely 13 patients (65%) and only 7 patients (35%) males. This is in accordance with a study conducted by Paragliola and colleagues conducted from 2018 to 2021 at the Fondazione Policlinico Universitario "A. Gemelli" IRCCS of Rome showed that there were 196 CAH patients dominated by 65% women while 35% were males [13]. Another study also conducted by Berglund and colleagues obtained 462 CAH children with 290 (62.8%) girls and 172 (37.2%) boys [14]. Studies in developing countries state that the diagnosis of boys with CAH is often missed, resulting in death without proper diagnosis and treatment. This makes the type of salt-wasting CAH more common in women [15]. The average age of CAH children in this study was 6.89 with the youngest patient being 2.9 years old and the oldest patient being 18 years old. In contrast to the study conducted by Gilban and his friend, there were 25 CAH children with an average age of 11.4 with the youngest age of 5 years and the oldest age of 17.9 years [7]. The education level of CAH children in this study occupies the most kindergarten and elementary school levels, which are 10 and 8 children, respectively. This is different from the statement of Zainuddin and his friends that most people occupy junior high school education [10]. The education level of parents of CAH children occupies the most in high school equivalent, which is 11 (55%), and in second place, not much different, has a bachelor's education level, which is 8 (40%). Another study also conducted by Larasati and her friends at the Dipenogoro National Hospital Semarang from March 2020 to October 29, 2020, showed that the education level of parents of CAH children mostly occupies the equivalent high school level, which is 59 (74%), while the remaining 21 (26%) have an undergraduate education level [16]. As many as 12 (60%) parents of CAH patients have an income of more than 1.2 million rupiah, almost the same as the data obtained from a study by Larasati and her friends only differ in the benchmark value, namely 60% of parents of CAH patients have an income of more than 2 million rupiah [16].

TABLE 1: Basic Characteristic.

Characteristic	Number (%)
Gender	
Male	7 (35%)
Female	13 (65%)
Age (years), (avg.2-4 years)	6,89
5-7 years	6 (30%)
8-12 years	7 (35%)
13-18 years	6 (30%)

Characteristic	Number (%)
Children's Education	10 (50%)
Kindergarten Elementary	8 (40%)
School Junior High School	1 (5%)
Senior High School	1 (5%)
Parent's Education Elementary	0 (0%)
School Junior High School	1 (5%)
Senior High School	11 (55%)
College	8 (40%)
Socioeconomic Level	
Low (<1,2million rupiah)	8 (40%)
Intermediate (1,2 – 6 million rupiah)	9 (45%)
High (>6 million rupiah)	3 (15%)
Total Sample	**20 (100%)**

The quality of life of children with congenital adrenal hyperplasia by age group is shown in Table 2. In this study, the results of the quality of life of CAH children in the age group of 2-4 years in the parental report had a lower total score than the control group, namely healthy children in the study conducted by Varni and colleagues [17]. When compared to the research conducted by Ferreira and his friends, the emotional function and school function scores of CAH children in the age group of 2-4 years in this study were lower than those of CAH children in the research of Ferreira and his friend, which were 80 and 62.5 [2]. Meanwhile, the social functionvalue of CAH children in the age group of 2-4 years had a higher score than CAH children in the research of Ferreira et al. Physical function values in the age group of 2-4 years have a score close to the research by Ferreira and his friend, which was 81.63 [2].

In this study, the age group of 5-7 years and 8-12 years had a lower total score than CAH children in the Rochmah and her friend's study, which were 89.79 (5-7 years old) and 80.48 (8-12 years old). The physical, social, and school function values of 5-7-year-olds in this study had lower scores than CAH children in the study of Rochmah and her friends, namely the scores were 100, 83, and 83 respectively. However, the emotional function value of 5-7-year-olds in this study was higher than that of CAH children in the Rochmah and her friend's study, which was 25. At the age of 8-12 in this study, the physical function and school scores were lower than that of CAH children in Rochmah and her friend's study, which were scores of 95 and 100.However, the emotional and social function values of 8- 12-year-olds in this study were higher than those of CAH children in Rochmah and her friend's study, which were 31.25 and 66.6 [8].

In the children's report, the 5-7 years and 8-12 age groups had higher total scores, physical function, emotional function, and social function than the control group in the study conducted by Ferreira and his friend. However, the school function scores of the 5-7-year-old and 8-12-year-old groups had lower scores than the control group in the study conducted by Ferreira and hisfriend, which were 72.21 and 72.79 [2]. Another study was also conducted by Gilban and colleagues, namely that the school function of CAH children was also reported to have decreased compared to the control group in the children's report [7]. In the parent's report, the 5-7- and 8-12-year age groups had higher total scores, physical functioning, emotional functioning, social functioning, and school functioning than thecontrol group in the study conducted by Ferreira and his friend. The exception for the school function value of the8-12-year age group in this study had a lower score than the control group in research by Ferreira and his friend [2]. When compared to the research conducted by Varni et al., the total scores of the 5-7- and 8-12-year age groups in this study had lower scores than the control group in the study of Varni and colleagues [17].

When compared to the previous study, children aged 13-18 years in this study had lower total scores, physical, social, and school functions than CAH children in the Rochmah and her friend's study, which were scores of 86.1, 100, 100, and 100 respectively. However, their emotional function had a higher score than CAH children in Rochmah and her friend's study, which was 25 [8]. In this study, the age group of 13-18 years had a total score that was not much different from the control group in the study conducted by Varni and colleagues. The total score of the control group in the report of the research child by Varni and colleagues was 83.65, while in the parent's report, the total score was 79.45 [17]. The values of physical function, emotional function, and social function of CAH children in the age group of 13-18years in the children's report had values not much different from CAH children in the research conducted by Ferreira and friends. However, the school function score was lower than that of CAH children in the research conducted by Ferreira and friends, which was 85. In the parents' report, the physical function and social function values of CAH children in the age groupof 13-18 years had values not much different from CAH children in the research of Ferreira and his friend, while the values of emotional function and school function had different values. Assess emotional function The age group of 13-18 years in this study was higher than that of Ferreira and his friend, which had a score of 55, while the school function value in this study was lower than that of Ferreira and his friend, which was 90 [2].

TABLE 2: Quality of life of children with congenital adrenal hyperplasia by Age Group.

PedsQL Score		Age (years)			
		2-4 years (n=6)	5-7 years (n=7)	8-12 years (n=6)	13-18 years (n=1)
		Average	Average	Average	Score
Children's report	Total score	-	76,62	78,62	80,43
	Physical Health Summary	-	80,61	89,58	90,63
	PsychosocialHealth Summary	-	74,76	72,78	75
	Emotionalfunction	-	77,14	74,17	70
Parent's report	Total score	75,6	78,42	76,63	82,61
	Physical Health Summary	79,69	85,27	89,06	87,5
	Psychosocial Health Summary	73,08	74,76	70	80
	Emotionalfunction	59,17	69,29	69,17	85
	Social function	85,83	82,86	79,17	95

Note: There was no average score in the age group of 13-18 years because only 1 sample was obtained.

TABLE 3: Quality of life of children with congenital adrenal hyperplasia by gender, children's education, parent's education, and socioeconomic level.

Characteristic	Number	Physical Health Summary	Emotional function	Social function	School function	Psychosocial Health Summary	Total score
Gender							
Male	7	85,1	71,92	78,97	67,7	72,8	76,97
Female	13	88,84	69,52	85,71	67,66	74,59	79,5
Children's Education							
Kindergarten	10	81,02	63,93	81,43	75,91	73,59	76,24
Elementary School	8	87,2	73,13	82,81	67,5	74,48	78,84
Junior High School	1	92,19	87,5	67,5	47,5	67,5	76,09
Senior High School	1	89,06	77,5	97,5	57,5	77,5	81,52
Parent's Education							
Elementary School	-	-	-	-	-	-	-
Junior High School	1	71,88	65	100	50	75	73,81
Senior High School	11	82,86	68,9	81,67	60,37	70,61	74,88
College	8	88,68	72,67	81,67	75,68	76,68	80,81
Socioeconomic Level							
Low (<1,2 million rupiah)	8	81,12	69,71	80,42	59,13	70,06	73,97
Intermediate (1,2-6 million rupiah)	9	90,52	71,25	85,94	73,36	76,9	81,6
High (>6 million rupiah)	3	78,72	70,83	75,83	65,83	70,83	73,54

The quality of life of children with congenital adrenal hyperplasia by gender, children's education, parent's education, and socioeconomic level were shown in Table 3. When comparing the quality of life of boys and girls in the study, girls have lower average scores of emotional function than boys which may be due to virilization. Increased androgen levels are more pronounced in women thus causing virilization and hirsutism.

In men, it is often asymptomatic or only with visible acne and or reduced fertility [18]. Research by Tschaidse and colleagues also said that girls with CAH had lower psychosocial scores than the control group [19]. In contrast to research conducted by Gilban and his friends, the psychosocial value of girls is higher than that of boys [7]. Another study was also conducted by Lašaitė and colleagues who said that women with congenital adrenal hyperplasia had a

higher perception of stress, anxiety, depression, disappointment, and worse environmental aspects than age-appropriate control women, while men with congenital adrenal hyperplasia had a perception of stress and emotional state that was no different from age-appropriate control men [20].

When viewed from the education of congenital adrenal hyperplasia children in this study, the higher the children's education level, the higher the total score value of PedsQL. It's just that at the junior high school level, the equivalent has a lower score which is possible because of the research sample factor, which is only 1 sample at the junior high school level so it affects the average total score. Research by Tschaidse and colleagues also states that higher levels of education are associated with a better quality of life [19].

Research by Alsulaimani and colleagues examined several reasons for non-compliance in the treatment of CAH children with 4 variables such as forgetfulness, unavailability of medications, difficulty getting prescriptions, and skipping or failing to book appointments with doctors. This will affect the quality of life of CAH children. The study conducted by Alsulaimani and colleagues reported that before the pandemic, 41 patients (75%) underwent laboratory testing every three months. After the pandemic occurred, the number of patients decreased to 37 patients (67%). Similarly, before the pandemic, as many as 40 patients (73%) were under control every three months. After the pandemic occurred, the number of patients decreased to 37 patients (67%), the reason was because there was a virtual clinic. The higher the level of parental education, the higher the level of compliance with CAH children's treatment [21]. It's the same as the result of this research is that the higher the education level of parents of CAH children, the higher the quality of life of CAH children. Another study also conducted by Yu and colleagues reported that parents of CAH children with higher levels of education and high income had better scores on psychosocial function and total scores [22]. In this study, families of CAH children with a middle socioeconomic level had the highest value in each function.

CONCLUSION

Congenital adrenal hyperplasia children at Dr. Soetomo Hospital Surabaya are at most 5-7 years old, dominated by women, the most children's education is kindergarten, parental education the most are high schools, and the most socioeconomic level is the middle level. The quality of life of children with congenital adrenal hyperplasia after the COVID-19 pandemic at Dr. Soetomo Hospital Surabaya, namely the age group of 2- 4 years has a total score of 75.6, the age group of 5-7 years has a total score of 76.62 (child report) and 78.42 (parent report), the age group of 8-12 years has a total score of 78.62 (child report) and 76.63 (parent report), and the age group of 13-18 years has a total score of 80.43 (child report) and 82.61 (parent report).

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