Description of Parents' Knowledge, Gluten Free Casein Free (GFCF) Intake Frequency and Autism Children Behavior in Palembang



Muzakar, Listrianah, Ike Surva Dewi, Ahmad Fudholi

Abstract: Autism is a representation, a general characterized by "a bunch of failure" to describe and categorize individuals social describing failures in behavior relationships. communication, and imagination ability. To develop ability on children with autism to be close to normal, diagnosis methods through early, integrated and intensive treatment were used. One type of therapy for children with autism is through food or the so-called Gluten Free Casein Free (GFCF) diet therapy. The type of this research was descriptive with cross sectional design. The population in the study were all students with autism who were still active following treatment with a sample of 36 people who were taken by using purposive sampling. Results showed that mostly there are 80.6% parents who have knowledge, 55.6% samples never eat foods containing gluten, 50% samples never eat foods containing casein, 77.8% samples have a good energy intake, 100% samples have good protein intake, and 80.6% samples have mild autistic behavior. From the results of the study, it is expected that the parents can increase knowledge about the GFCF diet in order to improve their diet and reduce behavior disorders in autism children.

Index Terms: Autism, knowledge, gluten, casein, autism behavior.

I. INTRODUCTION

Autism is a representation, general term characterized by "some failures". The term was introduced by a British Psychiatrist, Wing, to describe and categorize individual behaviors that illustrate failure in social relationships, communications, and imagination [1].Today's world autism prevalence reaches 15-20 cases per 10,000 children or 0.15-0.20% [2]. Based on the Autism Research Institute in San Diego, in 1987 the number of autistic individuals was estimated to be 1:5000 children or 0.02%. In 2005 this number increased to 1:160 children or 0.625%. In California, in 2002 it was concluded that there were 9 cases of children suffering from autism every day. In the United States, autism occurs in 60,000-15,000 children under 15 years of age.

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In the UK in early 2002, it is reported that the incidence of autism increased very rapidly, and suspected 1 from 10 children or 10% suffer from autism.

In Indonesia with a population of 200 million, the number of people with autism is increasing. In 2004, it was recorded that 475 thousand patients or 0.2375% and in every 150-200 children there are 1 child with autism or 0.5-0.67% [3]. Based on observations by the Indonesia Autism Foundation in South Sumatera in recent years, it is known that the number of children affected by autism is not less than 1,000 children under five years old [4]. According to data from Bina Autis Mandiri Foundation Therapy Palembang, the foundation takes care 100 autism children and 50 children are 3-6 years old.Based on diagnosis method, in order to develop the ability of children with autism to approach normal state, early, integrated, and intensive therapy must be conducted [5]. One type of therapy for children with autism is through food or so-called Gluten Free Casein Free (GFCF) diet therapy. According to Reichelt's research (1970), consuming gluten and casein will cause the same symptoms as heroin addicts in patients. So every source of casein and gluten should be removed from their diet and environment.

Gluten is a wheat flour protein and casein is a milk protein. Children with autism disorders often have impaired digestion of gluten and casein proteins. Gluten and casein proteins in the digestive system of autistic children are difficult to be broken perfectly into single amino acids and still in peptide form. The undigested peptide exits through the small intestine, enters the bloodstream and carried to the brain to the opioid receptor cells, which will cause central nervous system disorders and may affect perception, emotion, behavior and sensitivity.

Based on research conducted by Autism Research Institute to a number of parents who had autism children, it was found that 65% of parents reported progress on the development of children with GFCF diet. According to Knivsberg et al., there were significant positive changes in social isolation, communication ability, cognitive ability, motor ability aspects and decreased autistic behavior in the GFCF diet group compared to the non-GFCF diet group, meanwhile both exhibit significant positive changes in language ability [6].Based on Mashabi and Tajudin [2] research results, it is known that the high level of mothers' knowledge will affect the diet of autism children. Therefore, mothers should be more selective in food selection and have a good knowledge of diet therapy for autism children for the development of children's behavior.



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Based on the above background, researchers can formulate problems regarding the description of parental knowledge, the behavior of children with autism and GFCF diet and researchers will conduct research in the Yayasan Terapi Bina Autis Mandiri Palembang.

II. RESEARCH METHODS

Research method used in this research is descriptive with quantitative approach. Descriptive research is a research method conducted to describe a phenomenon that occurs in society. The research design used in this research is cross sectional that is the measurement and data collection of dependent and independent variables of each sample are assessed simultaneously and performed at one time simultaneously in Yayasan Terapi Bina Autis Mandiri Palembang.The population in this research were 100 autism children who were still actively participated in therapy in Yayasan Terapi Bina Autis Mandiri Palembang.

The sample is part of the selected population using purposive sampling, i.e. the technique of determining the sample by using the criteria that have been determined to be a sample.

A. Inclusion Criteria

Children aged 3-6 years who are still active following the therapist and apply the GFCF diet and accompanied by parents, and parents of children with autism who are willing to be interviewed and signed a statement letter to be respondents in Yayasan Terapi Bina Autis Mandiri Palembang.

B. Exclusion Criteria

The exclusion criteria is for children who have been out of Yayasan Terapi Foundation Bina Autis Mandiri Palembang and Parents of children who are not willing to be interviewed.

To determine the sample size was used formula:

$$d = Z_{1-\alpha/2}^2 \sqrt{\frac{pq}{n}} \sqrt{\frac{N-n}{N-1}}$$
(1)

where,

Z1- $\alpha/2$ = Confidence level of 95% (1.96) p = proportion of subject (0.5) q = 1 - P (1-0.5 = 0.5) d = Precision, set 10% (0.1)

N = Number of population

n = size of sample size

Based on the calculation results of the sample size, it was found that there were 36 samples in which 10% of them were reserves samples. The sampling technique was by determining the interval by using the formula

Ν

(2)

ⁿ Data analysis was done by using computerized SPSS data in univariate analysis to analyze each variable from research results by using frequency distribution table which describe dependent variable including autistic child behavior and independent variable including parents knowledge and consumption frequency of GFCF.

III. RESULT AND DISCUSSION

Based on the data showed in the Table 1, most children suffer from autism in the age group 4-6 years that was equal to 61.1%. While, there were 38.9% children suffer from autism in the age group 1-3 years. Autism has two basic types: autism from birth (classic autism) and regressive autism that usually occurs between the ages of 12-24 months after a period of development and normal behavior.

Childhood begins after a period of infancy, which is two years old until the age of 13 years for men and 14 years for women. The basis for development in childhood, among others, is to talk and build early social relationships with the environment. In children with autism, children will be difficult to meet these developments [7].

Table 1. Univariate analysis for age group

Category	Total	Total		
Category	n	%		
1-3	14	38.9		
4-6	22	61.1		
Total	36	100		

Table 2 shows that most children who suffer from autism is in boys that is equal to 83.3% while girls only amounted to 16.7%. These results are in line with Pratiwi's [8] study, which states that the prevalence of autistic patients is more common in males, i.e. 83.3%. According to Huzaemah [9], the ratio of autistic children between men and women is 2.6-4:1.

This is due to the presence of genes or some genes on the X chromosome that are associated with autism. Men who have only one X chromosome, do not have a backup when one other X chromosome is experiencing abnormality. Several studies have concluded that genes on the X chromosome are not the main cause of autism, but a gene on the X chromosome can affect social interactions and have a role in behavior related to autism.

Table 2. Univariate analysis for genre

Catagory	Total		
Category	n	%	
Boys	30	83.3	
Girls	6	16.7	
Total	36	100	

Based on the Table 3, from 36 samples most of the subject's parents income is around Rp. 2,500,000-5,000,000 (75%).

This finding is in line with research done by Syafitri [7], children with autism cost greater than normal children, this is what makes the family income determining an autistic child to get things that can support its development. Based on the data, generally the income of the sample family ranges from Rp.2,500,000-Rp 5,000,000 (35.5%), sample's family income of < Rp.2,500,000 is 6.5%, family income of Rp.5,000,000-7.500.000 is 19.4 %, family income of Rp.7,500,000-15,000,000 is 9.7%, family income of Rp.10,000,000-15,000,000 is 12.9%, family income of > Rp.15,000,000 is 16.1%.



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Children with autism have some disruption in their body, so it requires a considerable cost.

Costs incurred by parents for children with autism, among others, are for the needs of therapies, supplements and special foods, as well as allergy tests needed by children.

	Table	3. Univ	ariate ai	nalysis	for par	ent reve	enue
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Catagory (P p)	Tot	Total		
Category (Kp)	n	%		
<2.500.000	3	8.3		
2.500.000-5.000.000	27	75		
5.000.000-7.500.000	6	16.7		
>7.500.000	0	0		
Total	36	100		

Based on the Table 4, it can be seen from 36 respondents that most subjects' parental knowledge is about 80.6%. While the subjects whose parents have good knowledge is equal to 8.3%, and whose parents' knowledge is less is 16.7%. The questions asked in this study were each scored and then grouped into three categories: less, moderate, and good.

This research finding is in line with the research result done by Mujiyanti [11]. 66.7% of mothers have a good level of knowledge. Based on research conducted by Mashabi and Tajudin [2] about nutrition knowledge of parent with autistic child pattern indicate that high level of nutrition knowledge of parent will influence autistic child's diet. It means higher nutrition knowledge of parent can influence autistic child's diet and otherwise.

Table 4. Univariate analysis for parental knowledge

Category	Total		
	n	%	
Good	3	8.3	
Moderate	29	80.6	
Less	4	11.1	
Total	36	100	

Based on the Table 5, it can be seen from 36 respondents that most of the frequency of gluten-free consumption in children with autism is never (55.6%). While the frequency of gluten-free consumption in children with autism is sometimes equal to 36.1%. Frequency of gluten consumption in children with autism can be categorized to be frequent: 3-6x per week, sometimes: 1-2x per week, never: 0 per week/not consumed [8].

Removing gluten from food does not have a drastic direct effect, except in young children. Changes may only be visible within 3-4 weeks or more. Therefore, eliminating gluten should be at least for 3 months. After that, a reassessment the achieved progress of child is conducted. Many cases show that autism progress is achieved after undergoing gluten-free diets for 7-9 months. But according to Dr. Reichelt, there are also cases whose progress is only seen after running for 2 years [9]. Based on Reichelt's research, is found that removing the food sources of gluten and casein from the diet with autism brought significant progress, both in terms of behavior and physical condition of patients. Parents with autism also report that their children are experiencing rapid advancement, ranging from more controlled behavior, to increased concentration and learning ability.

 Table 5. Univariate analysis for gluten free consumption

frequency			
Catagory	Total		
Category	n	%	
Frequent	3	8.3	
Sometimes	13	36.1	
Never	20	55.6	
Total	36	100	

Based on the Table 6, it can be seen from 36 respondents that most of the frequency of casein free consumption in children with autism is never (50%). While the frequency of casein free consumption in children with autism is sometimes (38.9%). The frequency of casein consumption in children with autism can be categorized to be frequent: 3-6x per week, sometimes: 1-2x per week, never: 0 per week/not consumed. The effects of eliminating milk and all foods made from milk are quickly visible; it can be within 2-3 days in children, while in adults, it is 10-14 days, even usually faster than that. This diet needs to be done for three weeks.

Fable (5. Univariate	analysis for	casein-free	consumption
		free over one		

neg	uency	
Catagory	Total	
Category	n	%
Frequent	4	11.1
Sometimes	14	38.9
Never	18	50
Total	36	100

Based on the Table 7, it can be seen from 36 respondents that most of the subject's energy intake in the good category is 77.8%. This study is in line with the research conducted [10], that 40% of subjects have normal energy adequacy level. Although some samples do not consume some types of foods that are a source of energy such as foods containing gluten (bread, cakes, biscuits and so on), the sample gets enough energy intake from the food menu they consume.

Table 7. Univariate analysis for energy intake

Category	Total	
	n	%
Good	28	77.8
Less	8	22.2
Total	36	100

Based on the Table 8, it can be seen from 36 that most of the protein intake of the subject in either category is 100%. Although some examples do not consume some types of foods that are a source of protein such as milk, the high protein intake is presumably due to the high consumption of food sources of protein, both animal protein and vegetable protein.

Table 8. Univariate analysis for protein intake

Category	Total	
	n	%
Good	36	100
Less	0	0
Total	36	100

Based on Table 9, it can be seen from 36 respondents that most autistic children's behavior is in the category of moderate autism (80.6%).



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1168

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While the behavior of children with autism in the category of mild autism is 19.4%. Children in the mild autism category shows this conditions that are autistic children still show eye contact, although it does not last long, can give a little response when someone calls his name, show facial expressions, and in communicating can still be done in both directions even though only occasionally. Whereas in the moderate autistic category usually in this condition, the autistic child still shows little eye contact, but he does not respond when his name is called. Aggressive or hyperactive measures, self-harm, indifference, and stereotyped motor disorder tend to be somewhat difficult to control but can still be controlled [11].Autistic behavior can be handled with several steps including through medical treatment, psychological therapy, behavioral management, and dieting. The regulation of diet therapy can facilitate the achievement of other therapeutic outcomes. Improvement or deterrence of autistic behavior can be seen within 1-3 weeks for a GFCF diet. Related research that has been done in 2004 in Bogor obtained results that as many as 68.24% of children with autism showed improved behavior at the level of hyperactivity after diet therapy.

Table 9. U	J nivariate	analysis f	for autism	children	behavior
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Category	Total	
	n	%
Mild Autism	7	19.4
Moderate	29	80.6
Autism		
Severe Autism	0	0
Total	36	100

Based on Table 10, it is found that there was a significant improvement in the mean score of autistic behavior from initial admission therapy compared with current behavior score. The higher the behavior score means the autistic child's behavior is getting closer to the mild autism category.

Table 10. Autistic child description according to the average autistic children behavior score

a			
Category	Total		Average CD
	min	Max	Average \pm 5D
Initial behavioral	7	18	11.58 ± 3.341
score entering			
therapy			
Current behavior	15	26	18.39 ± 3.804
score			

IV. CONCLUSION

Based on the results of research that has been done on children with autism in YayasanTerapi Bina Autis

MandiriPalembang, it can be drawn thefollowing conclusions:

(i). Characteristics of respondents based on genre i.e. in men amounted to 83.3%. While in women only amounted to 16.7%. Characteristics of respondents based on the highest age in the age category 4-6 years amounted to 61.1%.

(ii). Most of the subject's parents income is around Rp. 2,500,000- 5,000,000 (75%).

(iii). Most parents' knowledge about autism and dietary sources of gluten and casein is moderate at 80.6%.

(iv). Most of the frequency of gluten-free consumption in subjects i.e. in the category never is 55.6%. And the

Retrieval Number F8355088619/2019©BEIESP DOI: 10.35940/ijeat.F8355.088619 Journal Website: <u>www.ijeat.org</u> frequency of casein free consumption on the subject i.e. in the category never is 50%.

(v). Most of the energy and protein intake of children with autism in the good category of energy intake is 77.8% and protein intake is 100%.

(vi). Most subject behaviors in the moderate autism category are 80.6%.

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1169