



CHARACTERISTICS OF PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER

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Abstract

Parents' social support is needed when having a child with Autism Spectrum Disorder (ASD) to control and prevent severity. The characteristics of parents who have ASD children are very important to identify in order to prevent stress. This study was aimed to identify the characteristics of parents with ASD children, namely age, education, gender, occupation, and social support. The results showed that parents with ASD children had the characteristics of age <40 years, higher education, female gender, and work. Social support is also strong from the four aspects, namely emotional, instrumental, informational, and reward support.

Keywords: Autism spectrum disorder, parent characteristics, social supports.

INTRODUCTION

Autism spectrum disorder (ASD) is a developmental disorder that includes deficits in social communication, social interactions, and limited and repetitive patterns of behavior, interests, or activities that persist throughout life. [1] The number of ASD sufferers continues to increase every year, both in developed and developing countries. WHO estimates the global prevalence of autism to reach 62 per 10,000 or one in 160 births. Meanwhile, based on data from the Center of Disease Control (CDC) in America in 2014, the prevalence of autism is 1 in 68 children. More specifically, 1 in 42 boys and 1 in 189 girls. [2] Meanwhile, the prevalence of autism in Indonesia is not certain. However, the Indonesian Autism Foundation stated that there is an increase in the prevalence of autism, where in a period of ten years, the number of children with autism in Indonesia is estimated to be 1: 5000 children, increasing to 1: 500 children. In 2000, the staff of the Psychiatry Department at the Faculty of

Medicine, University of Indonesia estimated that there were approximately 6,900 children with autism in Indonesia. It is estimated that in 2010 one per 300 children. Meanwhile, in 2015 it is estimated that one per 250 children. In 2015 it is estimated that there are approximately 140,000 people with the Autism spectrum in Indonesia (YAI, 2017). Meanwhile, data from the Center for Special Education Development of the Central Java Province Education Office in 2017, there were 550 autistic students from 15,292 special schools (blind, deaf, mentally retarded, and disabled). Among 530 students, the highest number of autism is in Surakarta, namely 117 students, Sukoharjo district 56 students, Semarang city 54 students and Semarang district 25 students.

The disorders inherent in ASD not only affect the individual being diagnosed but also affect parents, siblings, teachers and society. [3] Parents play an important role in educating children with ASD. [3] The role of parents is not limited to bringing children to therapy

institutions, sending them to special schools (SLB) or regular schools with inclusive education. Parents are required to be able to confirm the diagnosis, establish communication with experts and enrich their knowledge about autism. [4] Most parents only pay attention to the characteristics of autism without understanding how to handle it. Some parents only place their children in therapy institutions without providing better treatment such as guiding, motivating and instilling self-confidence in children. This causes delays in handling children with autism, and even exacerbates the problems that occur in children. [5]

Parents of children with ASD do not provide comprehensive handling to overcome problems that occur in their children because parents of children with ASD tend to experience higher stress compared to parents of children without developmental disorders or parents of children with other special needs. [6] A survey of 219 parents of children with ASD described that 30% of parents had moderate to severe anxiety levels, less than 20% had clinical depression. This study aims to identify the characteristics of the parents of children with autism disorder.

RESEARCH METHODS

The reference population in this study were parents of children with ASD. While the study population in this study were all parents of

children with ASD who attended the Semarang Special School. Sampling is done by sampling Random Allocation, which is a technique used for sampling based on certain considerations made by the researcher himself, proportionally based on the characteristics and characteristics of the previously known population. The subjects of this study were parents of children with ASD who attended SLB Semarang who met the inclusion criteria.

The sampling method was simple random sampling by fulfilling: a. Inclusion criteria 1) Parents of children with ASD who attend SLB Negeri Semarang. 2) Can read and write 3) Can communicate actively 4) Willing to be a respondent and sign an informed consent. b. Exclusion criteria 1) Parents who have children with ASD, with children over 17 years of age. 2) Children with ASD suffer from serious mental disorders or other comorbidities. c. Drop Out Criteria 1) The percentage of respondents is less than 80% in parent class activities. 2) Respondents refuse to do pre-test or post-test.

The research data which was carried out by the univariate test were data in the form of percentages with respondent characteristics based on age, education level, gender, type of work and family support. The data are categorized using predetermined measuring instruments, then the results of these categories can be analyzed to determine the mean, median, mode and standard deviation of each measured variable.

RESULTS

Distribution of Characteristics of Parents of Children with ASD

Table 1. Characteristics of parents of children with ASD

Characteristic	Group				P
	Intervention		Control		
	n	%	n	%	
Age					
< 40 years	19	63,3	11	36,7	0,071
> 40 years	11	36,7	19	63,3	
Sex					
Female	21	70,0	21	70,0	1,000
Male	9	30,0	9	30,0	
Education					
Low	0	0.0	4	6.7	0.112

High Occupation	30	100,0	26	86,7	
Work	19	63,3	14	46,7	0,299
Housewife	11	36,7	16	53,3	

Based on the table 1, it is known that the intervention group is mostly under 40 years of age (63.3 percent), most of them are female (70 percent), all are highly educated (100 percent), and most of them work (63.3 percent).). In the control group, it is known that most of them are over 40 years old (63.3 percent), most of them are female (70 percent), most are highly educated (86.7 percent), and most are housewives (53.3 percent). There was no difference in the age of the respondents between the intervention group and the control group with a p value of 0.071. There was no

gender difference between the intervention group and the control group with a p value of 1,000. There was no difference in the education of the respondents between the intervention group and the control group with a p value of 0.112. There was no difference in the occupation of the respondents between the intervention group and the control group with a p value of 0.299. Based on these results, it can be concluded that the respondents in the intervention group and the control group came from a population that had the same characteristics.

Table 2. Social support for intervention groups

Item No.	Statement	Mean	Evaluation
Emotional Support			
1	Husband or wife listen to what the subject is telling	2.67	Strong
2	Have a friend to share the joys and sorrows that the subject has felt while having a child with ASD	3.00	Strong
3	Feeling the people around, ready to hear the outpouring of the subject	2.40	Less strong
4	Feeling people around, ready to be invited to exchange ideas	2.43	Less strong
5	Both family and neighbors try to show concern for the subject	2.53	Strong
Instrumental Support			
6	Husband or wife accompany when the subject finds it difficult to care for my child	3.17	Strong
7	If I have financial difficulties to pay for my children's education and needs, my family and neighbors will lend money to me	1.87	Less strong
8	Can I go to someone to help look after my child	2.80	Strong
9	Husband or wife accompanies the child while the child is studying	3.40	Strong
10	Husband prioritizes children's education	3.33	Strong
Informational Support			
11	I got advice and information on how to care for a child with ASD	2.90	Strong
12	I was reminded to always be patient and not to differentiate between my child with ASD and my child without developmental problems	3.07	Strong

13	I asked the teacher at my child's school about my child's development	3.07	Strong
14	Tell each other about parenting experiences with ASD with parents of children with other ASD	2.93	Strong
15	Some are believed to help solve problems	2.57	Strong
Award/appraisal Support			Strong
16	Give praise for what I do	2.47	Strong
17	Some believe in my ability to raise and care for children	2.90	Strong
18	Everything I do is considered important	2.90	Strong
19	Always do something to appreciate me	2.83	Strong
20	Give encouragement when I feel desperate about parenting	2.90	Strong
			2.81 Strong

Based on table 2, it can be seen that the average social support for the intervention group, namely emotional support, instrumental

support, informational support, and reward support, has a strong category.

Table 3. Control group social support

Item No.	Statement	Mean	Evaluation
Emotional Support			
1	Husband or wife listen to what the subject is telling	2.93	Strong
2	Have a friend to share the joys and sorrows that the subject has felt while having a child with ASD	3.03	Strong
3	Feeling the people around, ready to hear the outpouring of the subject	2.30	Less strong
4	Feeling people around, ready to be invited to exchange ideas	2.50	Less strong
5	Both family and neighbors try to show concern for the subject	2.47	Less strong
Instrumental Support			
6	Husband or wife accompany when the subject finds it difficult to care for my child	3.17	Strong
7	If I have financial difficulties to pay for my children's education and needs, my family and neighbors will lend money to me	2.17	Less strong
8	Can I go to someone to help look after my child	2.60	Strong
9	Husband or wife accompanies the child while the child is studying	2.60	Strong
10	Husband prioritizes children's education	3.37	Strong
Informational Support			
11	I got advice and information on how to care for a child with ASD	3.10	Strong
12	I was reminded to always be patient and not to differentiate between my child with ASD and my child without developmental problems	2.97	Strong

13	I asked the teacher at my child's school about my child's development	3.10	Strong
14	Tell each other about parenting experiences with ASD with parents of children with other ASD	2.90	Strong
15	Some are believed to help solve problems	2.70	Strong
Award/appraisal Support			Strong
16	Give praise for what I do	2.70	Strong
17	Some believe in my ability to raise and care for children	2.87	Strong
18	Everything I do is considered important	2.83	Strong
19	Always do something to appreciate me	2.67	Strong
20	Give encouragement when I feel desperate about parenting	3.00	Strong
			2.80 Strong

Based on table 3, it can be seen that the average social support for the control group, namely emotional support, instrumental support, informational support, and reward support, has a strong category.

DISCUSSION

The characteristics of parents with children with autism in this study were the age characteristics at most <40 years old, higher education, mostly a woman and working. This results research in line with Elizabeth et al., 2018 are 21% of mothers had a high school diploma or General Equivalency Diploma or less with ASD children.[7] Social support for parents with children with autism, namely in terms of strong emotional support, seen from the two parents communicating and giving advice, having good relationships with neighbors in dealing with autistic children, and also parents having friends to share with each other related to autism. Instrumental support from parents is also strong, it can be seen from the husband or wife accompanying when they have difficulty caring for children, husband and wife cooperate with each other in caring for children, informational support is also strong, this can be seen from parents getting advice and information about how to care for children with ASD, people parents are reminded to always be patient and not differentiate between children with ASD and children without developmental disorders, parents ask teachers at school about their child's development, tell each other about parenting experiences with ASD with parents of children with other ASD, and someone is

trusted help solve problems. And the support for awards is also very strong, this can be seen from give praise for what I do, some believe in my ability to raise and care for children, everything I do is considered important, always do something to appreciate me, and give encouragement when I feel desperate about parenting. In theory, parents with ASD children experience stress, but this study has not shown this, because stress research on parents with ASD children is still in the research process. However, if seen from the social support, parents with ASD have strong social support from the aspects of emotional support, instrumental support, informational support, and appreciation support. Based on the other research, mother of children with ASD exhibit similar cortisol levels to those of combat soldiers, parents who have a child with cancer, and individuals who suffer from posttraumatic stress disorder. [8] Social support is very important to have and enhanced by parents with ASD children, for ASD-related interventions are mostly applied in the home and, moreover, are not curative but rather palliative. Individuals with ASD often exhibit problematic behaviors in addition to the core symptoms of ASD, which can be more problematic than the core symptoms themselves. Research has shown that both core symptoms (e.g., language and social deficits, limited or repetitive behavior) and behavioral problems (e.g., tantrums, disobedience) increase levels of parenting stress and can negatively impact parents' mental health. [9] The results of other studies suggest that informal social support and social media are

perceived as more helpful than formal support, which parents usually perceive as neutral. Overall, the study suggests that meeting the parental support needs of children with ASD remains a priority. [9] Parents' perceptions of their child's core ASD symptoms were slightly higher than comparable estimates published in the United States [10] indicating the need for parents to provide support. Overall, the results showed that the social support used by parents was very strong and provided the fourth function of support, namely emotional, instrumental, informational, and rewarding.

CONCLUSION

Characteristics of parents with ASD children are age <40 years, higher education level, a mother and have a job, social support is also strong from the four supports, namely emotional, instrumental, informational, and appreciation.

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