

# Resilience And Parenting Stress For Mothers Who Have Children With Autism Disorder During The COVID-19 Pandemic In Indonesia

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Article Info	Abstract
Article History:	The COVID-19 pandemic has created a risk in families, especially for those
Submitted: April 8 <sup>th</sup> , 2023	with children with special needs. An inappropriate response to the impact of
Accepted: Dec 28 <sup>th</sup> , 2024	the pandemic has the potential to make the existing condition worse. The
Published: Dec 30 <sup>th</sup> , 2024	implementation of social restrictions causes all activities to be carried out at home, both working and studying. The positive thing is that parents have
Keywords:	more time to take care of their children. However, there are also parents who
Autism Disorder; Children;	complain of fatigue and find it difficult, especially those who have children
Covid-19 Pandemic;	with special needs such as autism. The closure of treatment centers such as
Parenting Stress; Resilience	speech therapy and physical and social skills has an impact on the
	development of their basic skills. This is a challenge for parents in raising
	them in the current situation. The aim of this study was to understand the
	influence of resilience towards parenting stress on mothers of children with
	autism disorder in the COVID-19 pandemic. The research design used was
	cross-sectional. The population in this study were mothers of a child with
	autism disorder who attended the Pembina Special School in Yogyakarta,
	Indonesia. The sampling technique used was total sampling. Linear
	regression analysis was used in the study. The study result showed p-value
	0.023 < 0.05, which means that there is an influence on the level of resilience
	with parenting stress experienced by mothers who have children with
	autism disorder during the COVID-19 pandemic. The resilience level of
	mothers was at a moderate level, although mothers' parenting stress was
	low. Parenting guidance and assistance for children with autism disorder
	needs to be done. This aims to improve coping strategies and family
	resilience during the COVID-19 pandemic.

#### **INTRODUCTION**

The situation of Covid-19 Pandemic has affected to all sectors of life, including health and education. Government policy on social restrictions such as lockdown has also changed life of people with autism. School and other care center closure brings new challenges to parents who have children with autism disorder in taking care of them. During the pandemic, children do fewer physical activities and have more access to *smartphone* in following their online class so it disrupts sleep rhythm and causes other physical problems. Fewer social interactions also affect children's development and can contribute to bigger psychological problems in the

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future [1]. This also contribute stressors to parents. The challenges that parents are facing are related to the parents and children with autism disorder, family, professionals and community [2].

Nationally, there is 12.5% of corona cases in children of 0-18 years old. It means that 1 of 8 children was confirmed to suffer from covid-19. On the other hand, there is a percentage of 3-5% of case fatality rate on children which makes Indonesia the first country with the highest number of child deaths with covid-19 in the world [3].

Children are vulnerable. This vulnerability is more at risk to children with special needs and disabled children. The ministry of women empowerment and child protection carries out protection efforts in disaster management by prioritizing vulnerable groups through rescue, evacuation. security, and health and psycho-social services [4]. The ministry of women protection empowerment and child conducts some strategies and comprehensive and integrated approaches in facing emergency phase of Covid-19 pandemic through the General Guidelines for Child Protection handling Covid-19 developed in the spirit of the principles of children's rights, namely nondiscriminatory, provides best interests for children, the right to life, continuity and development, as well as respect for children's opinions.

Parents who have children with special needs have a bigger problem than average parents. Parents who have children with special needs have greater challenges and experiences in terms of physical, social, emotional and child and growth development. In addition, parents who have children with special needs are also at risk of experiencing psychological and mental health problems. such as: anxiety. depression, divorce and sleep disorders [5]. The results showed that parents who have autistic children would experience greater mental health problems than parents who have children with other disabilities [6].

Autism is a collection of symptoms (syndrome) caused by nerve damage. Symptoms are visible already before the child reaches the age of three. People with autism show deviant communication disorders. Such communication disorder can be seen in the form of speech delays, non-speech, speech in incomprehensible language (planetary language), or speech only by imitating (echolalia). In addition to communication disorders, children also showed impaired interaction with people around them, both adults and their peers [7].

The level of parenting stress in parents who have children with special needs is significantly higher than the level of parenting stress in parents who do not have children with special needs [8]. Parents who have children with special needs experience parenting stress and have greater burdens compared to parents who do not have children with special needs [9]. Parents who have autistic children are required to be accustomed to having a different role than before. Parents feel stigmatized bv children's limitations, experience burnout due to additional care demands, socially isolated, and burdened with the financial costs of parenting, especially in the current pandemic situation where some parents may experience job loss. This will trigger prolonged stress and cause parenting stress.

Resilience is a person's ability in assessing, overcoming, and improving themselves from the downturns and tribulations in life [10]. Resilience is also something that can make a person able to carry out their duties and solve problems well [11]. Parents who have high resilience will be able to provide optimal care. On the contrary, if parents have low resilience level, they will not be able to treat children reasonably and ignore them. The characteristics of autistic children will affect parenting stress and psychological distress because mothers have a role in the social behavior of autistic children [12]. Therefore, it is necessary to study resilience level in mothers of children with autism disorder towards parenting stress during covid-19 pandemic. This can be an evaluation and follow-up plan to increase family resilience in the covid-19 pandemic which will affect children's growth and development.

# **METHODS**

This study employed a cross-sectional design using anonymous on-line questionnaires. Considering the current environmental requirements due to the COVID-19 pandemic and the enhanced internet connectivity of participants, the online survey process was found to be most relevant, convenient and efficient.

The study was conducted in April-July 2021 at SLB N Pembina Yogyakarta. SLB N Pembina is one of the biggest special schools in Yogyakarta which has 240 students from Elementary School to Senior High School. SLB N Pembina has children with special needs with ASD, Down Syndrome, Retardation Mental, ADHD and Slow Learner. The purpose of this study was to determine how the influence of resilience and parenting stress on mothers who have children with autism disorder during the covid-19 pandemic.

The purposive sampling was carried out as sampling technique by looking at students' guardian data based on inclusive and exclusive criteria set by the researcher. Inclusive criteria in this study were: guardians of students with autism disorder, ability to fill out the questionnaire on Google Form, and willingness to be respondents. While the exclusion criteria were guardians of students whose children were not active in school for 1 month and were experiencing physical or psychological pain. The data collection tool in this study was a questionnaire. The first questionnaire was adopted from the Brief Resilience Scale (BRS), which used as many as 6 items to measure maternal resilience [13]. The BRS instrument has passed the validity test with a correlation coefficient ranging from 0.30 to 0.69, which means that the questionnaire has a strong level of validity. The result of the alpha Cronbach reliability test ( $\alpha$ ) was also 0.8 to 0.91, which indicates that the question items from the BRS are reliable. Meanwhile, the second questionnaire to measure parenting stress consisted of 29 items adapted from the parenting stress scale [14]. The results of the parenting stress instrument validity test with the correlation Pearson product were between 0.364 - 0.762 > r-table (0.361), while the alpha Cronbach reliability test ( $\alpha$ ) result was 0.915.

The data analysis in this study used the Linear Regression Test. Data analysis was performed using a statistical program with a significance level of 0.05. Descriptive analysis analvze was used to of sociodemographic data included education, occupation, guardian, and children's sex. Chi-square test was employed to determine the relationship between these independent variables and characteristics respondent.

Ethical clearance was obtained from the Ethics Committee of Surya Global Institute of Health Science Yogyakarta, with No. 5.28/KEPK/SSG/IV/2021. All participants received a complete explanation regarding the research and provided their informed consent before taking part in the research.

## RESULTS

There were 30 respondents in the study. Most of the participants, as many as 14 participants, were senior high school graduates (22.2% of the respondents). Only one of the participants graduated from elementary school (1.6%). It can be concluded that most of the mothers did not

work as there were 22 participants or 73.3% of the participants were housewives. Meanwhile, 8 of the participants worked (26.7% of the participants). 29 participants, or 96.7% of the parents take care of their children and there was only one parent whose child was taken care by someone else (3.3%). On the other hand, 83.3% or most of the participants' child is a boy (25 of the participants).

Table 2 shows a significant relationship between children's sex and parenting stress in mothers of children with autism disorder with p value of 0.025. On the other hand, educational background's p value of 0.621, profession's p value of 0.662, and parenting's p value of 0.741 do not have any significant relationship with parenting stress in mothers of children with autism disorder.

According to table 3, *p value* is 0.023, which is less than 0.05. Therefore, it can be inferred that there is an influence of resilience towards parenting stress in mothers of children with autism disorder. The R value is 0.172 which means the level of resilience influences parenting stress and was experienced by 17.2% of the mothers.

Table 1 Distribution of characteristics of participants (n=30)				
Indicators	f	%		
Education				
Undergraduate	11	17.5		
Senior high school	14	22.2		
Junior high school	4	6.3		
Elementary school	1	1.6		
Job				
Housewife	22	73.3		
Working	8	26.7		
Parenting				
Parents	29	96.7		
Other than parents	1	3.3		
Children's sex				
Boys	25	83.3		
Girls	5	16.7		

Table 2		
Relationship between respondents' characteristics		
and parenting stress in mothers of children with		
autism disorder (n=30)		

autism disorder (n=30)				
Variable	Total, n	X2	Р-	
			value	
Education				
Undergraduate	11	4.410	0.621	
Senior high school	14			
Junior high school	4			
Elementary school	1			
Job				
Housewife	22	0.825	0.662	
Working	8			
Parenting				
Parents	29	0.599	0.741	
Other than parents	1			
Children's sex				
Boys	25	1.167	0.025*	
Girls	5			
Note: * significance was measured using Chi Square				

Note: \*significance was measured using Chi-Square Test

Table 3		
Analysis on linier regression of influence of		
resilience towards parenting stress in mothers of		
children with autism disorder		

Variable	p-value	R Square		
Resilience	0.023	0.172		
Parenting Stress	0.025	0.172		

## DISCUSSION

Before the outbreak of covid-19 pandemic, the duty of accompanying children to learn lessons was often delegated to teachers. The pandemic situation, however, encourages parents to play a more important role. In addition, the closure of treatment centers such as speech, physical and social skill therapy has an impact on their children's basic skills development. This is a challenge for parents in caring for their children in this situation.

Based on table 1, most of the children (83.3%) with autism disorder are boys. Boys are four times more susceptible to autism than girls [15]. The cause of susceptibility to disorders of the development of the nervous system is in the genes. The comparison between boys and girls who have autism disorder is 4:1 [16].

Table 2 shows a significant relationship between resilience level and parenting stress in mothers who have autistic sons. The results of the previous studies have shown that stress that mothers experienced was caused by behavior of boys who experienced problems in toilet training dan and playing with their genital (genital touching). The masturbation and toileting problems as compulsive behaviors in children with ASD can also lead to mothers' apprehension. Mothers' depression in the adolescent group was probably due to concerns about their children's antisocial behavior. It is possible that these children's behavioral characteristics were recognized as serious problems by their mothers, which in turn can negatively affect their mental health. Children's age does not matter, but emotional and technical support to mothers can be critical in maintaining mothers' mental well-being [17]. The result of interviews to some mothers revealed that their children still wet the bed and play their genital organ.

In terms of parenting, most of the children (96.7% of the participants) are taken care by their parents and there are 73.3% of mothers who do not work (housewife). Working mothers will experience higher level of parenting stress compared to nonworking mothers. Events in workplace and other conditions related to work have short and long term effects in family life, i.e., negative interaction in job will influence parents and children's interaction [18]. The results of interview with some mothers show that since the covid-19 pandemic they have lost their job so they have more time with their children. Mothers state that they understand their children's characteristics more and they get to know more about what their children want. The covid-19 pandemic has its own wisdom for parents, because they can directly monitor their children, so that they can find out the difficulties their children face and of course will create closer relationship between parents and children because parents play a role in solving their children's difficulties [19].

This study shows that there is a significant influence of resilience towards parenting stress in mothers of children with autism disorder in the covid-19 pandemic. Families with high level of resilience will have low stress level [20]. Another study also states that positive experience that mothers have in taking care of children with autism disorder influences stressor level being experienced [21].

Most of the mothers have moderate level of resilience. There were twelve mothers who still could not control their emotion so they found it difficult to think rationally in certain situations, and they were less confident with their ability in taking care of their children. In addition, fourteen of the were mothers worried about their children's future, especially with the current pandemic situation and they have not been able to overcome the fears that have occurred to them. One of the concerns that mothers experienced is that their children have comorbidities such as anxiety disorder and depression [21].

Concerns that mothers experience can affect the children's recent mental state. The situation that forces people to be isolated causes children with autism disorder experience stress and adaptation disorder. Furthermore, mothers of children with autism disorder are faced with concerns, such as future children's welfare, children's ability to function independently, and the acceptance of the surrounding environment towards the presence of children with autism disorder [22].

Parenting stress is excessive anxiety and tension and is related to the role of parents and interactions between parents and children [23]. Parenting stress will push parents to malfunctioning in parenting causing a discrepancy in the parent's response to conflicts originating from the child and from the parents.

The covid-19 pandemic has triggered an increase of stress and emotion in parents

who have children with autism disorder. The stress experienced is influenced by characteristics and repeated aggressive behavior that children with autism disorder show [24]. In addition, parents' stress is also influenced by parents' characteristics, children's characteristics and disrupted interactions between parents and children [14]. Having children with autism disorder can give negative impacts to mothers' mental and emotional health. Mothers of children with special needs have higher stress level and lower mental health compared to those who do not have special children [16]. Social support can influence mothers' mental health [11].

In this study, the level of parenting stress in mothers is low as shown by the data that 19 mothers could control response towards stressors in taking care of their children. Social characteristics such as parents' educational background and parents' psychological characteristics play the most important role in the process of qualified parenting [25]. This is supported with the data that most of the mothers graduated from Senior High School. Awareness on parenting is also an important investment to create resilience towards parenting stress. By having awareness of parenting, the tiring duty of parenting will not be taken as a burden [26].

Mother's low level of parenting stress shows that mothers have good social integration, emotional closeness with children, high health level, do not experience depressions symptoms, do not experience rigid and frustrating restrictions in maintaining self-identity and gets support from their surroundings [27]. Low level of parenting stress shows that mothers have good coping mechanism so they can control their emotion and solve their problems well.

## CONCLUSION

The covid-19 pandemic has triggered an increase of stress and emotion in mothers of

children with autism disorder. Resilience involves a positive adaptation and change within someone. Mothers who have an ability to solve problems well will improve their positive relationship with their autistic children. Mothers with high level of resilience will have a good coping ability so they are able to overcome the stressors encountered. This will influence quality in parenting and children's growth and development.

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# BIBLIOGRAPHY

- Tarnoto N, Nuryana Z. Digital Intervention and Peer-Support Group to Promote Mental Health of Children and Adolescents During COVID-19: Practical Guidelines From Indonesia. Asia-Pacific Journal of Public Health 2022:4–5. https://doi.org/10.1177/10105395221129 104.
- [2] Daulay N. Home education for children with autism spectrum disorder during the COVID-19 pandemic: Indonesian mothers experience. Research in Developmental Disabilities 2021;114:103954. https://doi.org/10.1016/j.ridd.2021.10395 4.
- [3] Indonesian Pediatrician Association. Pess Conference Perhimpunan 5 Profesi Dokter Melonjaknya Kasus COVID-19 di Indonesia (Press Conference of the Association of 5 Medical Professions Regarding High COVID-19 Cases in Indonesia). Jakarta: 2021.
- [4] Republik Indonesia. Indonesian Law No. 24 on Disaster Management. Indonesia: 2007.
- [5] Chen S, Chen S, Li X, Ren J. Mental Health of Parents of Special Needs Children in China during the COVID-19 Pandemic. International Journal of Environmental Research and Public Health 2020;17:9519. https://doi.org/10.3390/ijerph17249519.
- [6] Blakeley-Smith A, Reaven J, Ridge K, Hepburn
  S. Parent-child agreement of anxiety symptoms in youth with autism spectrum disorders. Research in Autism Spectrum Disorders
  2012;6:707-16.

https://doi.org/10.1016/j.rasd.2011.07.020

- Sengupta K, Lobo L, Krishnamurthy V. Educational and Behavioral Interventions in Management of Autism Spectrum Disorder. Indian Journal of Pediatrics 2015;84:61–7. https://doi.org/10.1007/s12098-015-1967-0.
- [8] Jenaabadi H. The study and comparison of stress levels and coping strategies in parents of exceptional (mentally retarded, blind and deaf) and normal children in Zahedan. Procedia - Social and Behavioral Sciences 2014;114:197–202. https://doi.org/10.1016/j.sbspro.2013.12.6 84.
- [9] Shyam R, Govil D. Stress and Family Burden in Mothers of Children with Disabilities Objectives : 2014;1:152–9.
- McLean S, Halstead EJ. Resilience and stigma in mothers of children with emotional and behavioural difficulties. Research in Developmental Disabilities 2021;108:103818. https://doi.org/10.1016/j.ridd.2020.10381 8.
- [11] Taylor ZE, Conger RD. Promoting strengths and resilience in Single-Mother families. Child Development 2017;88:350–8. https://doi.org/10.1111/cdev.12741.
- Ozturk Y, Riccadonna S, Venuti P. Parenting dimensions in mothers and fathers of children with Autism Spectrum Disorders. Research in Autism Spectrum Disorders 2014;8:1295–306. https://doi.org/10.1016/j.rasd.2014.07.001
- Smith BW, Dalen J, Wiggins K, Tooley E, Christopher P, Bernard J. The brief resilience scale: Assessing the ability to bounce back. International Journal of Behavioral Medicine 2008;15:194–200. https://doi.org/10.1080/10705500802222 972.
- [14] Abidin. Parenting stress index 3rd edition: Professional manual. 1995.
- [15] Gamsiz ED, Viscidi EW, Frederick AM, Nagpal S, Sanders SJ, Murtha MT, et al. Intellectual disability is associated with increased runs of homozygosity in simplex autism. American Journal of Human Genetics 2013;93:103–9. https://doi.org/10.1016/j.ajhg.2013.06.004.
- [16] Miranda A, Mira A, Berenguer C, Rosello B, Baixauli I. Parenting stress in mothers of children with autism without intellectual disability. Mediation of behavioral problems

and coping strategies. Frontiers in Psychology 2019;10:464. https://doi.org/10.3389/fpsyg.2019.00464.

- [17] Kido K, Fujita K. Correlation between Child Behavior and Depression in Mother with Autism Spectrum Disorders Child. Journal of Maternal and Child Health 2021;06:475–85. https://doi.org/10.26911/thejmch.2021.06. 04.09.
- [18] Rajgariah R, Malenahalli S, Venkatesh K. Parenting stress and coping strategies adopted among working and non- working mothers and its association with sociodemographic variables: A cross-sectional study. Clinical Epidemiology and Global Health 2021;9:191–5. https://doi.org/10.1016/j.cegh.2020.08.013
- [19] Gloria. Maintaining Good Mental Health While at Home with Positive Family Activities. 2020.
- [20] Gayatri M, Irawaty DK. Family Resilience during COVID-19 Pandemic: A Literature Review. The Family Journal: Counseling and Therapy for Couple and Families 2022;30:132–8. https://doi.org/10.1177/10664807211023 875.
- [21] Papadopoulos D. Mothers' experiences and challenges raising a child with autism spectrum disorder: A qualitative study. Brain Sciences 2021;11:1–16. https://doi.org/10.3390/brainsci11030309.
- [22] Fuentes J, Hervás A, Howlin P, Asd E, Party W. ESCAP practice guidance for autism: a of evidence summary based recommendations for diagnosis and treatment. European Child & Adolescent Psychiatry 2021;30:961-84. https://doi.org/10.1007/s00787-020-01587-4.
- [23] Ilias K, Cornish K, Kummar AS, Park MSA, Golden KJ. Parenting stress and resilience in parents of children with autism spectrum disorder (ASD) in Southeast Asia: A systematic review. Frontiers in Psychology 2018;9. https://doi.org/10.3389/fpsyg.2018.00280.
- [24] Alhuzimi T. Stress and emotional wellbeing of parents due to change in routine for children with Autism Spectrum Disorder (ASD) at home during COVID-19 pandemic in Saudi Arabia. Research in Developmental Disabilities 2021;108:103822. https://doi.org/10.1016/j.ridd.2020.10382 2.

- [25] Brooks JB. The Process of Parenting. 9th ed. New York, USA: Mc Graw Hill; 2013.
- [26] Parkes A, Sweeting H, Wight D. Parenting stress and parent support among mothers with high and low education. Journal of Family Psychology 2015;29:907–18. https://doi.org/10.1037/fam0000129.
- [27] Willner P, Rose J, Stenfert Kroese B, Murphy GH, Langdon PE, Clifford C, et al. Effect of the

COVID-19 pandemic on the mental health of carers of people with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities 2020;33:1523–33. https://doi.org/10.1111/jar.12811.