KNOWLEDGE AND CHARACTERISTICS DO NOT AFFECT THE STRESS OF MOTHERS CARING FOR AUTISTIC CHILDREN IN INDONESIA: A CROSS-SECTIONAL STUDY

Pengetahuan Dan Karakteristik Tidak Mempengaruhi Tingkat Stress Ibu Merawat Anak Autis di Indonesia: Studi Cross-Sectional

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ABSTRACT

Background: Autistic Spectrum Disorder is an incurable developmental disease. Parents who have autistic children must have the ability to care for them because they have differences especially in socializing, so parents experience stress in caring for them. **Purpose:** To analyze the relationship between the characteristics and level of knowledge of mothers with the level of stress in caring for children with autism in bekasi city. **Methods:** A cross-sectional design with a sample of 67 respondents. Used Parenting Stress Scale questionnaire and the knowledge level questionnaire. The validity test was conducted on 30 respondents at Ananda therapy school with the results of the stress level questionnaire as many as 14 valid statement items, the knowledge level questionnaire 20 valid statements. **Results:** The results of the analysis of age characteristics with stress levels obtained a p-value of $0.534 > \alpha 0.05$, the results of economic status with stress levels obtained a p-value of $0.871 > \alpha 0.05$, the results of the level of education with stress levels obtained a p-value of $0.402 > \alpha 0.05$ and the results of the analysis of the level of knowledge with stress levels obtained a p-value of $0.389 > \alpha 0.05$. **Conclusion:** There was no relationship between the characteristics of age, economic status, level of education and level of knowledge of mothers with the level of stress in caring for autistic children.

Keywords: stress, autism, autistic spectrum disorder, parenting stress scale, knowledge

ABSTRAK

__Latar Belakang:__ Autistic Spectrum Disorder merupakan penyakit perkembangan yang tidak dapat disembuhkan. Orangtua yang memiliki anak autis harus memiliki kemampuan dalam merawat, sebab memiliki perbedaan khususnya dalam bersosialisasi, sehingga orangtua mengalami stress dalam merawat. __Tujuan:__ Untuk menganalisis hubungan karakteristik orangtua dan tingkat pengetahuan ibu dengan tingkat stress dalam merawat anak autis di kota bekasi. __Metode:__ Desain cross-sectional menggunakan purposive sampling dengan sampel 67 responden. Menggunakan kuesioner Parenting Stress Scale dan kuesioner tingkat pengetahuan ibu. Uji validitas dilaksanakan pada 30 responden di sekolah terapi Ananda dengan hasil kuesioner tingkat stress sebanyak 14 item pernyataan valid, kuesioner tingkat pengetahuan 20 pernyataan valid. __Hasil:__ Hasil dari analisis karakteristik usia dengan tingkat stress didapat p-value yaitu $0,534 > \alpha 0,05$, hasil dari status ekonomi dengan tingkat stress didapatkan p-value sebesar $0,871 > \alpha 0,05$, hasil dari tingkat pendidikan dengan tingkat stress didapatkan p-value sebesar $0,402 > \alpha 0,05$ dan hasil dari analisis tingkat pengetahuan dengan tingkat stress didapatkan p-value sebesar $0,389 > \alpha 0,05$. __Kesimpulan:__ Tidak ada hubungan karakteristik usia, status ekonomi, tingkat pendidikan serta tingkat pengetahuan ibu dengan tingkat stress dalam merawat anak autis.

__Kata Kunci:__ Stress, Autis, Gangguan Spektrum Autis, Skala Stress Perawatan Orangtua, Pengetahuan

INTRODUCTION

Autistic Spectrum Disorder (ASD) is a broad and diverse developmental disorder that affects brain function. This disorder often affects creativity, communication, and social interaction (Norlita, 2021). Symptoms of autism include difficulties forming positive social relationships and engaging in peer play and social interaction. Autism-related communication problems include unique language use and play patterns, delayed or missing speech, and a propensity to fixate on certain parts of objects (Pangestu & Fibriana, 2017).

According to the World Health Organization (WHO) in 2018, 1 in 160 children worldwide were affected by autism spectrum disorder (ASD). Indonesia's population is currently more than 270.2 million, with an estimated increase of around 3.2 million children diagnosed with autism (BPS, 2020). Indonesia had 144,102 autistic children in 2019, according to the Special School Statistics Data Center (SLB). (KEMENDIKBUD, 2020).

Parents who have autistic children, experience stress in raising their children. Recent research by (Johansson *et al*., 2021) showed that mothers tend to have higher levels of parental stress and depressive symptoms than fathers. Stress is an individual's reaction to events, stimuli, responses, and external interpretations that exceed their potential to cope (Miranda *et al*., 2019). The realization that there is no cure for autism can increase stress in parents (Dunn *et al*., 2001). Parental stress can also be increased by children's behavior, particularly aggressive and improper social behavior linked to autism (Nuha *et al*., 2020). Lack of understanding about autism can cause parents to have difficulty dealing with their child's behavior. The impact if parents who have autistic children experience stress is that they are prone to depression and often blame themselves and feel helpless (García-López *et al*., 2016).

Due to the high expenses of their education and care, autistic children's parents are more stressed when they are experiencing financial difficulties. Play therapy, biomedical therapy, physical therapy, behavioral therapy, and several other therapies are among the available treatment choices (Suteja, 2014). Most parents of special needs children come from lower socioeconomic classes and frequently have erratic employment like farmworkers or casual laborers. Thus, their income fluctuates, making it difficult for them to satisfy their family's demands (Jannah, 2020).

The behavior, lifestyle, and motivational techniques of children with autism are only a few aspects of child development that require parental knowledge of how to educate and care for them. A variety of factors, including knowledge, parental education, and the environment, might influence how parents understand autism (Puspitasari & Hikmah, 2019). Parental knowledge is increased with information, which effectively reduces parental anxiety. Increasing parental knowledge leads to increased awareness and alignment of actions with the information obtained (Notoatmodjo, 2008).

The results of the study (Maynola, 2017) showed a correlation between parental understanding and handling of autistic children at SLB AL-IKHLAS Garegeh Bukittinggi in 2017. Of the 35 respondents, 21 (75.7%) showed a high level of parental knowledge. Ruminem's study (2019) examined the relationship between knowledge and maternal attitudes in caring for autistic children at home in Balikpapan City. It showed that 18 respondents (58.1%) have a high level of understanding of autism.

Parental stress levels and age have a positive correlation (Kusumastuti, 2014). An individual's susceptibility to stress rises with age. (Irkhami, 2015) stated that the ages of 21–40 and 40–60 are when people are most susceptible to stress. A person's age and the amount of stress they endure are closely related. An individual's physical state and organ function deteriorate with age, making them more vulnerable to stress. Age is an important factor, because the older a person is, the more easily they experience stress (Azizah *et al.*, 2023).

The level of education of parents who have autistic children is reflected in their ability to provide appropriate and effective care for their children (Januwarsih & Triastuti, 2020). Several previous studies have shown that mothers who have autistic children tend to experience stress caused by the burden of care, ignorance about handling autism, and less supportive economic and educational conditions. However, although there have been many studies discussing the relationship between parental stress and autism, there is still limited research that specifically highlights how the characteristics and level of knowledge of mothers as primary caregivers correlate with stress levels.

A preliminary study conducted by researchers through interviews with 10 mothers who have autistic children at a therapy center in Bekasi showed that 6 mothers with sufficient knowledge about caring for autistic children did not experience symptoms of stress. However, 4 mothers with low knowledge admitted to experiencing symptoms of stress, such as fatigue, anxiety, and crying because they were confused about caring for their children. This indicates that the level of knowledge of mothers can affect their stress levels (Nazhifah, Not Pulished).

This study aims to answer the gap of knowledge that specifically examine the relationship between maternal characteristics (such as age, education, and economic status) and their level of knowledge with stress levels in caring for autistic children. The novelty of this study lies in its approach that targets mothers as the main population and utilizes two standardized instruments to measure stress and knowledge and is conducted at three autism therapy centers in Bekasi which are the main references for the local community.

Therefore, this study was conducted with the aim of analyzing the relationship between the characteristics and level of maternal knowledge with the level of stress in caring for autistic children in Bekasi City.

METHOD

Study Design

This study used a quantitative method with a cross-sectional approach to identify the relationship between parental characteristics and stress levels in mothers with autistic children.

Location and Time of the Study

The study was conducted at three autism therapy places in Bekasi, namely Satria Kid Center, Rumah Terapi Amanah, and Rumah Pusat Autism, in January - June 2023.

Population, Sample, and Sampling Technique

The population of this study consisted of all mothers who had children with autism in three therapy locations, with a total of 67 respondents. The author selected these three locations because they had the highest percentage of autism kid survivors among the 67 respondents, which was in line with the population.

The research sample was selected using the purposive sampling approach. This approach was chosen because there are not many cases and the number of kids with

autism issues was a phenomenon that society was still unfamiliar with. Inclusion criteria were: 1) Mothers who have autistic children 2) Mothers who were willing to be respondents 3) Domiciled in the Bekasi area. Exclusion criteria were: 1) Mothers who were not willing to be respondents 2) Those who were not domiciled in Bekasi 3) Mothers who have children with special needs other than autism.

Ethical Clearance

This study obtained ethical approval from the Research Ethics Committee of the Muhammadiyah University of Purwokerto with the code of ethics number KEPK/UMP/38/IV/2024.

Informed consent

This study has informed consent to ensure that research participants were given clear and complete information about the objectives, procedures, risks, and benefits of the study, so that they can give their consent voluntarily, and that participant data is kept confidential and used only for research purposes.

Instrument

The research instrument used a parenting stress scale questionnaire and a parental knowledge level questionnaire. The researcher has conducted a re-validation test of each questionnaire item involving 30 respondents. According to these results, the parental stress scale assessment tool's Corrected Item-Total Correlation showed that out of the 18 statements, 14 were deemed accurate (r table value >0.361) and 4 were deemed erroneous (r table value <0.361). Similarly, of the 20 statements in the parental knowledge level questionnaire, 20 are deemed legitimate if the r-count result is more than 0.444.

The results of the reliability test obtained a Cronbach's Alpha value of 0.877 on the parenting stress scale questionnaire and 0.903 on the parental knowledge level questionnaire. Then each questionnaire was declared reliable because the Cronbach's Alpha number was > 0.6. If the score > 24.55 seen from the cut of point using the mean value, it was categorized as high stress, a score <24.55 was categorized as low stress. For the knowledge level questionnaire, a score of <56% was categorized as low knowledge, a score of 56% -75% was categorized as sufficient knowledge. A score of 76% -100% was categorized as good knowledge.

Data Analysis

This study used two methods of data analysis, namely univariate and bivariate analysis. Univariate analysis was presented in a frequency distribution table for the variables age, education level, economic level, and knowledge level. Based on the age distribution (26–35 years, 36–45 years, 46–55 years, and 56–65 years), education level which included as basic education are primary school (SD), secondary education, which includes junior high school (SMP), high school (SMA), and vocational high school (SMK), and higher education, which includes bachelor's degrees (S1, S2, S3). There are three levels of parental education. The economic level of knowledge, which includes salaries that are less than standard salary and more than standard salary, was displayed graphically. Then, the association between these variables was tested using a Chi Square test in bivariate analysis.

RESULT

Univariate Analysis

Table 1. Distribution of Respondent Characteristic Frequency

Respondent Characteristic	Frequency (n)	Percentage (%)
Age		
26-35	28	41,8%
36-45	27	40,3%
46-55	6	9,0%
56-65	6	9,0%
Total	67	100%
Education		
JHS	5	7,5%
SHS	22	32,8%
University	40	59,7%
Total	67	100%
Salary		
<5000000	11	16,4%
5000000	18	26,9%
>5000000	38	56,7%
Total	67	100%
Knowledge Level		
Low	5	7,5%
Sufficient	46	68,7%
Good	16	23,9%
Total	67	100%

The results of the univariate analysis have the aim of being able to review the frequency distribution of each variable studied. The variables analyzed include age, economic status, education level, knowledge level, and stress level. The results of the frequency distribution were presented in the form of a diagram.

Bivariate Analysis

Table 2. Correlation of Age and Stress Level

Age	Category of Stress Level				Total		P-Value
	Low Stress		High Stress				
	N	%	N	%	N	%	
26 – 35 years	13	19,4%	15	22,4%	28	41,8%	
36 – 45 years	16	23,9%	11	16,4%	27	40,3%	0,710
46 - 55 years	4	6%	2	3%	6	9%	
56 - 65 years	3	4,5%	3	4,5%	6	9%	

Table 2 portrayed that the majority of respondents aged 36-45 years experienced low stress, which was 16 people (23.9%). Statistical analysis confirmed that there was no significant relationship between age and stress levels in respondents of mothers caring for autistic children in Bekasi City, as evidenced by a p-value of 0.710> α 0.05. Thus, "H0 failed to be rejected" which means that there was no relationship between age and stress levels of mothers caring for autistic children in Bekasi City.

Table 3. Analysis of Correlation of Economi Status and Stress Level

Salary	Category of Stress Level				Total		P-Value
	Low Stress		High Stress				
	N	%	N	%	N	%	
<Rp 5.000.000	6	9%	5	7,5%	11	16,4%	
Rp 5.000.000	10	14,9%	8	11,9%	18	26,9%	0,978
> Rp 5.000.000	20	29,9%	18	26,9%	38	56,7%	

Table 3 showed that the majority of respondents with income > Rp 5,000,000 experienced low stress, which was 20 people (29.9%). Statistical analysis confirmed that there was no significant relationship between economic status and stress levels in respondents of mothers caring for autistic children in Bekasi City, as evidenced by a p-value of 0.978 > α 0.05. Thus, "H0 fails to be rejected" which means that there was no relationship between economic status and stress levels of mothers caring for autistic children in Bekasi City.

Table 4. Analysis of Correlation of Education Level and Stress Level

Education	Category of Stress Level				Total		P-Value
	Low Stress		High Stress				
	N	%	N	%	N	%	
JHS	2	3%	3	4,5%	5	7,5%	
SHS	11	16,4%	11	16,4%	22	32,8%	0,694
University	23	34,3%	17	25,4%	40	59,7%	

Table 4 stated that the majority of respondents with college education experienced low stress, which was 23 people (34.3%). Statistical analysis confirmed that there was no significant relationship between education level and stress level in respondents of mothers caring for autistic children in Bekasi city, as evidenced by the p-value of 0.694> α 0.05. Thus, "H0 fails to be rejected" which means that there is no relationship between education level and stress level of mothers caring for autistic children in Bekasi city.

Table 5. Analysis of Correlation of Knowledge Level and Stress Level

Knowledge Level	Category of Stress Level				Total		P-Value
	Low Stress		High Stress				
	N	%	N	%	N	%	
Low	3	4,5%	2	3%	5	7,5%	
Sufficient	26	38,8%	20	29,9%	46	68,7%	0,649
High	7	10,4%	9	13,4%	16	23,9%	

Table 5 revealed that the majority of respondents with sufficient knowledge levels experienced low stress, which was 26 people (38.8%). Statistical analysis confirmed that there was no significant relationship between the level of knowledge and the level of stress in respondents of mothers caring for autistic children in Bekasi City, as evidenced by the p-value of 0.649> α 0.05. Thus, "H0 fails to be rejected" which means that there was no relationship between the level of knowledge

and the level of stress of mothers caring for autistic children in Bekasi City.

DISCUSSION

This study did not find any significant relationship between age, education level, economic status, or maternal knowledge level with stress levels in caring for autistic children. The results of the bivariate analysis showed that all these variables had a p value > 0.05, which means that statistically there was no significant relationship between these factors and maternal stress levels. This finding showed that although variables such as young age (25–35 years), higher education, good economic status, and sufficient knowledge can theoretically contribute to reducing stress, this has not been proven practically significantly in the context of mothers caring for autistic children.

When compared to previous studies, these results differ from several studies that showed a significant influence between these factors and stress levels. For example, research by Yumni & Ramadhani (2023) and Fatwa (2020) found that economic status was related to stress levels because financial stability can reduce psychological burdens. Research by Jeniu *et al*. (2017) stated that higher education levels are positively correlated with the ability to manage stress, while Nisak *et al*. (2020) found that good knowledge about autism can reduce maternal stress levels. Even Rahayu (2019) revealed that most parents with autistic children experience high levels of stress. However, in this study, this relationship was not found so that the results were not entirely in line with the existing literature.

Several reasons can explain why no significant relationship was found in this study. One of them is the diversity of personal experiences, coping mechanisms, and levels of social support possessed by each mother.

Age or higher education does not automatically guarantee adequate ability to manage stress if the individual does not have good environmental support or coping skills. In addition, stress in the context of caring for autistic children is very complex and multidimensional, so it cannot be explained with just one or two demographic variables. Knowledge about autism is not necessarily able to reduce the emotional stress that arises from the daily challenges faced by mothers, especially if it is not accompanied by emotional acceptance, psychological resilience, and adequate social support.

This study has several strengths such as the selection of relevant variables and the right bivariate analysis method to test the relationship between variables. In addition, the respondents involved were also in a fairly representative age range and came from various educational and economic backgrounds. However, there are also several weaknesses that need to be considered. First, the limited number of samples can reduce statistical power in detecting relationships that may be weak but significant. Second, this study did not directly measure psychosocial variables such as social support, coping mechanisms, and maternal psychological conditions, even though these factors have the potential to influence stress levels. Third, the cross-sectional research design does not allow for assessing causal relationships or dynamics of stress changes over time. Therefore, further research is needed with a more comprehensive approach, such as a longitudinal design and multi-variate measurement to better understand the factors that influence maternal stress in caring for autistic children.

CONCLUSION AND SUGGESTION

The results of the study indicate that there is no relationship between stress levels and knowledge levels, education levels, or

economic status. Further researchers can conduct research with various variables that are not the same as the relationship between characteristics and maternal stress levels in caring for autistic children.

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AUTHOR CONTRIBUTION

Hana Najla Nazhifah contributed to data collection, data analysis, manuscript writing, literature review. Renta Sianturi contributed to the data collection process, data analysis, and manuscript writing.

CONFLICT OF INTEREST

The authors declare there is no conflict of interest.

DECLARATION OF ARTIFICIAL INTELLIGENCE (AI)

The authors affirm that no artificial intelligence (AI) tools, services, or technologies were employed in the creation, editing, or refinement of this manuscript. All content presented is the result of the independent intellectual efforts of the authors, ensuring originality and integrity.

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