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Autistic Children Parenting Stress

A Study on Parents Taking Caring of Children with Autism during the COVID-19 Pandemic

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ABSTRACT

Autism Spectrum Disorder (ASD) is a group of brain development disorders characterized by stereotyped behavior and deficits in communication as well as social interaction. This usually appears before the age of three. Handling children with autism in the COVID-19 pandemic situation can be challenging for parents. The national home quarantine has caused children with autism, who used to attend special schools, to do distance learning and stay at home all day. This study aimed to determine the descriptions of stress in parents taking care of children with autism. The characteristics of the participants of the study were parents who take care of children with autism during the COVID-19 pandemic and there were 71 of them. The Parenting Stress Scale (PSS) by Bernard Jones was used to measure the parenting stress. The study revealed that the stress on parents taking caring of autistic children during the COVID-19 pandemic was below average. The descriptions of stress that were found to exist were dimensions of pleasure (emotional benefit and personal development) and dimensions of strain (feelings of sacrificing time, energy and costs).

Keywords: Autism spectrum disorder, Parenting stress, COVID-19 pandemic.

1. INTRODUCTION

Children are a gift from God that is coveted by every married couple. The child will be the hope of the next generation that is better than the child's parents. Parents always expect their children to develop well and perfectly physically, socially, mentally, and cognitively [1]. But in reality these desires sometimes do not match our expectations. Especially parents who get their children as children with special needs [2]. Based on the 2012 Susenas data, it was found that the estimated population of Indonesia with disabilities was 2.45% and around 39.9% of that number had more than one disability or disability [3].

Autism Spectrum Disorder (ASD) is a group of brain development disorders characterized by stereotypical behavior and deficits in communication and social interaction, usually appearing before the child is three years old [4]. Research conducted by the Center for Disease Control and Prevention in 2013 stated that the prevalence of autism in the world currently ranges from 0.15-0.20%, including Indonesia. A study estimates that there is an increase in the number of children with autism in Indonesia to

reach 6,900 children/year [5]. Children with autism have a tendency to behave in a different way or in different ways for each child. Excessive behavior includes aggressive behavior towards oneself (self-abuse), such as hitting, biting, scratching and tantrum behavior such as screaming, crying, and jumping. While deficient behavior is characterized by speech disorders, sensory deficits and inappropriate emotions. This behavior causes parents who have children with autism to be extra in providing supervision to their children, in other words the role of the family, especially parents, is important in caring for children with autism [6].

The family is the first and foremost environment for children to contribute to mental and physical development in their lives. In the family environment, the most important role is parents because it is related to attention, availability of quality time and parental involvement to be very influential for children [7]. However, caring for a child with autism can generate stress for parents if the demands of the parent's role exceed their coping resources, without being able to restore balance through the usual methods and strategies. Parental stress of children with autism

reached clinically significant levels in 77% of cases [8].

24 The initial reaction that appears when parents find out that their child is diagnosed with Autism Spectrum Disorder can be in the form of shock, inner turmoil, sadness, stress, guilt, disappointment, unable to accept reality until they are reluctant to communicate with others [9]. This is supported by the results of research by Schieve, Blumberg, Rice, Visser and Boyle (2017) which states that the stress level of parents is higher when having children with autism than the stress level of parents who have normal children.

In 2020, Corona Virus Disease (COVID-19) originating from Wuhan, China has spread in Indonesia. Along with the increasing number of cases and the death toll, the government declared this situation a pandemic. A number of steps have been taken to be able to resolve this pandemic, one of which is to carry out social distancing movements. This greatly affects children with autism because the tendency for repetitive behaviors that are usually done such as school and therapy are stopped. This situation also has an impact on parents who feel overwhelmed in providing care to children with autism, such as the statement given by one mother who cares for children with autism stating that she has experienced difficulties and fatigue that has doubled. Before the pandemic, the child routinely did therapy, while now activities are very limited causing excessive tantrums (S. Yulianti, personal communication, June 01, 2020).

According to Berry and Jones, stress is a reaction to the environment when a loss or loss occurs. In parenting stress, stress is characterized by loss of control and freedom and financial, energy and time burdens that exceed parental resources.

According to Abidin, parenting stress is anxiety and tension that goes beyond limits and is specifically related to the role of parents and interactions between parents and children [10]. Based on the definitions above, it can be concluded that parenting stress is a condition where there are obstacles in the roles and responses between parents and children that are not appropriate.

Parenting stress consists of 2 dimensions, namely a) the pleasure dimension, the positive emotional component of parenting that brings emotional benefits such as love, joy, happiness, pleasure and feelings of self-development and b) the strain dimension, the negative emotional component of parenting, which

involves demands for various resources such as time, energy, and money, as well as prohibitions, feelings of shame, and control [11].

There are six determinants of stress in parenting, namely child behavior problems, child intelligence, child age, family cohesion, family income, and maternal psychological well-being [12].

Child behavior problems regarding child behavior problems were significantly associated with overall parental stress, as well as with maternal feelings about maternal competence and acceptance.

Child intelligence regarding the child's cognitive function will be significantly related to maternal stress, but cognitive function is not associated with the outcome variable. This is because parenting stress is more related to the challenge of managing difficult behaviors than dealing with a child's mental disorder.

Child age regarding the ethics of children experiencing developmental delays as they age, family stress increases when parents develop a more realistic view of their child's future.

Family Cohesion is significantly correlated with stress and parental isolation. Mothers will experience less stress and feelings of isolation and feel more confident in their parenting skills when they have help and support from other family members.

Family income such as the impact of socio-economic status has an impact on the stress of mothers to take care of their children resulting in a decrease in the ability to accept their children.

Maternal psychological well-being such as a mother suffering from severe psychological problems, the mother may not have sufficient personal resources available to others or her child, thus increasing feelings of isolation and lack of confidence related to parenting skills can affect psychological well-being.

Lazarus argues that stress occurs when a person experiences demands that exceed the resources he has to make adjustments, this means that stress conditions occur if there is a gap or imbalance between demands and abilities. A demand is something which if not met will have unpleasant consequences for the individual. So stress does not only depend on external conditions but also depends on the cognitive processing mechanism of the conditions faced by the individual concerned [13].

When faced with a situation that can cause stress, the reaction of each individual is different. Some of these responses are reactions that are not realized, while others are realized by the individual to immediately do coping. Lazarus divides these reactions into 4 categories, namely a) cognitive reaction, b) physiological reaction, c) emotional reaction and d) behavioral reaction [14].

Cognitive reactions to stress include the results of the appraisal process such as beliefs about the danger or threat contained in an event or beliefs about its causes. Cognitive responses also include unconscious stress responses such as distance, inability to concentrate, impaired performance in cognitive tasks, and intrusive, repetitive and abnormal thoughts. Cognitive stress symptoms include obsessive thinking and an inability to concentrate.

Physiological reactions in the face of stress, the body mobilizes itself to deal with the stress. The liver secretes more glucose to lubricate muscles and hormones are released to stimulate the conversion of fat and protein into sugar. The body's metabolism increases in preparation for the energy demands of physical activity. Heart rate, blood pressure, and breathing increase and muscles tense up. At the same time, unnecessary activities such as digestion are reduced, saliva and mucus will dry up and instead increase the amount of air inhaled. This psychological response is the result of the work of several body systems to deal with stress.

Emotional Reaction is cognitive assessment or interpretation of the environment associated with needs, goals, expectations, or concerns is what determines how a person's emotional response. The dominance of negative emotions such as anxiety, depression, and anger is an indication that the individual concerned assesses the situation as something that causes stress and is felt to hurt or harm (harm/loss), or poses a threat that something bad will happen. can injure or harm the existence of the individual.

Behavioral reactions are related to the emergence of a new behavior as an individual effort to reduce or eliminate the stressful conditions they experience. Behaviors that arise such as smoking, reducing or overeating, exercising excessively, consuming alcohol or illegal drugs, and so on. This behavioral reaction appears depending on the stressor faced, the behavior against the stressor directly (fight) and away from or

withdrawing from the threat (flight) are the two most extreme reactions.

Based on the explanation above, the researcher wants to know the description of stress in caring for Autism Spectrum Disorder children during the COVID-19 pandemic.

2. METHODS

The characteristics of the participants that researchers will take are parents who take care of children with autism spectrum disorders during the COVID-19 pandemic. Researchers obtained subjects through purposive sampling with accidental techniques, namely taking samples anytime and anywhere by meeting the requirements as samples from a certain population. The number of samples in this study were 71 participants.

This research is a kind of descriptive statistic. Descriptive statistics function to describe or provide an overview of the object under study through sample or population data [15].

The measurement of Parenting Stress variable uses The Parenting Stress Scale (PSS) which was developed by Berry and Jones. It consists of 18 items. PSS includes two dimensions, namely the pleasure dimension (positive component) consisting of 8 items and the strain dimension (negative component) consisting of 10 items. PSS was measured by assessing each item with 4 Likert scales, namely (1) Strongly Disagree, (2) Disagree, (3) Agree and (4) Strongly Agree. The higher the score, the higher the stress. This measuring tool is a self-report that was created specifically to measure the level of stress experienced by parents due to the presence of children. PSS focuses on the stress caused by the role of parents through the description of the relationship between parents and children and their feelings about it [10].

The first dimension of the Parental Stressor Scale is pleasure, which has 8 positive statements. An example of one of the statements contained in the Parental Stressor Scale dimension in the pleasure dimension is "I am happy with my role as a parent". The second dimension of the Parental Stressor Scale is strain, which has 10 negative statements. An example of one of the statements contained in the strain dimension is: "The main source of stress in my life is my child".

Table 1. Blueprint of the Parenting Stress Scale

Dimension	No. Items	Total
Pleasure	1,2,5,6,7,8,17,18	8
Strain	3,4,9,10,11,12,13,14,15,16	10

The internal consistency reliability coefficient for this variable is 0.899 and after removing 2 items, namely numbers 3 and 8, which have the corrected item total correlation below 0.2, the internal consistency reliability coefficient value for this variable becomes 0.918.

After distributing the questionnaires, the researcher will input the data into the Statistical Product and Service Solution (SPSS) program. Then after being input, a reliability test will be carried out to determine the value of Cronbach's Alpha.

3. RESULT AND DISCUSSION

The descriptions of respondents in this study are generally shaped by age, gender, education, occupation, income, status, child's age, child's gender and child's education. Based on the age of the respondents, respondents aged between 25-40 years amounted to 42 people with a percentage of 59.2%, and respondents aged 41-65 years amounted to 29 people with a percentage of 40.8%. Based on gender, there are more female respondents than male with a total of 49 people with a percentage of 69% and the number of respondents with male sex is 22 people with a percentage of 31%. Based on education, respondents who have primary education as many as 2 people or 2.8%, respondents who have high school education as many as 31 people or 43.7%, respondents who have diploma degree as many as 13 people or 18.3%, respondents who bachelor degree as many as 24 people or 33.8%, respondents who have magister degree are 1 person or 1.4%. Respondents in this study were dominated by respondents with high school education, namely 43.7%.

Based on occupation, respondents who have jobs as private employees are 34 people or 47.9%, respondents who have jobs as civil servants are 12 people or 16.9%, respondents who have other jobs are 25 people or 35.2%. Respondents in this study were dominated by respondents who had jobs as private

employees, namely 47.9%. Based on income, respondents who have income < Rp. 1.250,000 as many as 12 people or 16.9%, respondents who have an income of Rp. 1.250.000- as many as 5 people or 7.0%, respondents who have an income of Rp. 3.750.000- as many as 13 people or 18.3%, respondents who have an income of Rp. 5.000.000- as many as 16 people or 22.5% and respondents who have income > Rp. 6,500,000 as many as 19 people or 26.8%. Respondents in this study were dominated by respondents who had income > Rp. 6,500,000 which is 26.8%.

Based on status, respondents with married status were 65 people or 91.5%, respondents with divorced status were 3 people or 4.2%, respondents with widower/widow status were 3 people or 4.2%. Respondents in this study were dominated by respondents with a married status of 91.5%. Based on the number of children, 22 respondents or 31.0% had 1 child, 33 respondents or 46.5% had 2 children and 16 respondents or 22.5% had children between 3-5. Respondents in this study were dominated by respondents who had 2 children, namely 46.5%. Based on the data obtained regarding as 7 respondents or 9.9% have children with general school education, 6 respondents or 8.5% have children with inclusive school education, 53 respondents or 74.6% have children with school education with special needs, and 5 respondents or 7.0% have children with home schooling education. Respondents in this study were dominated by respondents who had children educated in schools with special needs, namely 74.6%.

Stress in this study consisted of two dimensions using a scale of 1 to 4 and had a hypothetical mean of 2.5, while the empirical mean of total stress was 1.915. The empirical mean score is lower than the hypothetical mean score. Thus, the stress of respondents can be said to be below average. Low stress levels are influenced by the pleasure dimension, which is higher than the strain dimension, which can be interpreted by respondents caring for children with autism during the pandemic as emotional benefits such as love, joy, happiness, pleasure and feelings of self-development, rather than demands for time, energy and money. This affects the involvement of respondents, as can be seen from respondents who provide active support in learning at home, collaborate with other parents to plan activities, and always

discuss ¹⁸ teachers when there are problems in the learning of children with autism.

For further research is needed to find which factors the best for predicting low stress of parents with autistic child.

¹⁶ **4. CONCLUSION**

Based on the results of research conducted on ²⁸ description of parenting stress on parents caring for children with autism spectrum disorders during the COVID-19 pandemic, it shows that parenting stress is in the below average category.

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