

The Effect an Stress Assessment-Based Family Coping Model on Caring Behavior of School-Age Children with Autism

Abstract

Background: Families who assume the limitations and negative impacts of having an autistic child as a major stressor tend to have a severe stress level, which results in maladaptive family coping and low caring behavior, so failure of autistic children occurs. This study aimed to analyze the effect of family coping models based on stress assessment to caring behavior of school-aged autistic children. **Materials and Methods:** Quasi-experimental research was conducted on parents of 7–12 years old autistic children in center autism Surabaya, Indonesia. A large sample was used and the rule of thumb was used in sem, 9 indicators \times 12 observed variables = 108. Parents were classified into a control group of 54 people without treatment and a control group of 54 people with treatment, who were given an application of randomly determined coping model. Data were collected from May to July 2022 using a questionnaire. Two-way test of variance using Wilcoxon signed ranks was used, and the difference test between groups uses Mann–Whitney U. **Results:** The difference test between in the controlled group shows any significant differences in family coping ($z = 0.13$) and ability the care for school-age autistic children ($z = 0.08$). The difference test between samples in the treatment group shows that there are significant differences in family coping ($z = 5.04$) and ability to care for school-age children autistic ($z = 5.08$). The difference test between the control and treatment groups shows that there are significant differences in family coping ($z = 5.75$) and the ability to care for school-age children autistic ($z = 7.00$). **Conclusions:** There is a significant difference on family coping and caring behavior between the control and treatment groups, which is going to be good. It was shown that creating an adaptive family coping was necessary.

Keywords: Autistic, behavior caring child, coping model, stress assessment

Introduction

Autistic children who have hyperactive, aggressive, and passive behavior tend to facing a difficulty of controlling emotion, crying, laughing, or easily getting angry without any reason. Insufficient information and awareness of the parents regarding autism cause autistic children to become isolated and a nightmare for most of the parents and are going to become a big stressor.^[1] The parents of children with autism spectrum disorders are at higher risk of experiencing acute and chronic stress compared to the parents of children with other developmental disorders and the parents of children without disabilities.^[1,2]

Autistic data in Indonesia show around 3.2 million autistic children of around 270.2 million Indonesian population,^[3] and data on autistic students who attend special schools show 144,102,^[4] who

are surely with different family coping, perhaps adaptive or maladaptive. Research results show that parental stress is caused by severity level and sustainable nature of autistic characteristics.^[5] Additionally, the stress of having a child with autism can give negative effects to the couple's relationship^[6] and lead to divorce (23.5%) compared to parents who have children without developmental disabilities (13.8%).^[7] The parents of children with autism convey a lower degree of relationship satisfaction than other parents.^[8] This condition can certainly trigger a stress in parents of autistic children. The condition of families who think of the existence of autistic children with limitations in social behavior, sudden behavior of rejecting the presence of other people language decline,^[9] and the negative impacts caused by the presence of autistic children as major stressors tend to have a severe level of stress. Severe stress of

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families can result in the care pattern that tends to be more authoritarian and permissive and can create a maladaptive family coping. The role of parents, that is, guidance and support, is one of the assistances that can be provided and is largely determined by the family's coping, providing the parenting patterns of caring the autistic children.

If the family's coping is maladaptive, a lingering sadness feeling, guilty feeling, and blaming each other among family members occur. Therefore, parents will provide inappropriate treatment to the school-aged autistic children. The behavior of caring for school-age autistic children without considering the characteristics and abilities of autistic children can cause failure in physical, psychological, and mental growth and development,^[10] which results in the loss of the nation's next generation because autistic children also take a part in determining the future of the nation.^[11] Families with adaptive coping will be able to increase optimally love and attention to the school-age autistic children, so they can optimize the developmental ability of autistic children.^[12] The efforts achieving adaptive coping of families can be achieved by increasing the family ability of evaluating stress to have a mild level of stress or no stress.^[13]

The research results have been related to coping strategies of parents with autistic children and stress triggers with autistic children and have influenced parental relationships. However, a few researchers have focused on the related dynamics within the family that related to the autistic child caring behavior. In this article, we attempt to apply the coping model that influenced the caring of autistic children from the study of family coping model development – based on internal stress assessment on behavior of caring autistic children. Previous coping model development has described factors that influence stress, predictors, moderators, coping, and the result of caring child autistic ability from families who have children with autism.^[10] Implementing the family coping model, we describe stress assessment, family coping strategies to autistic children, and behavior of caring school aged autistic children as supported by the literature with the limitations of model^[10] in implementing to this population. The family coping model was expanded, including addition in resources of family members and the behavior results of caring autistic children. Although we exclusively focused on families with autistic children, this new model can be also applied to families that have children with other specially needed as well as other family structures (for example, divorced parents and multigenerational parenting).

The research aims to analyze the influence of family coping on behavior of caring the school-aged autistic children. The research also applied a method of coping assessment by assessing the stress level and behavior of caring for school-aged autistic children with a questionnaire. This questionnaire is able to show the specificity of family coping based on more accurate and correct stress

assessment on a group of families with autistic children according to the characteristics.

Materials and Methods

Quasi-experimental research was conducted on parents of school-aged autistic children in Autism Center Surabaya, Indonesia. This research is an application of research results on the development of coping models based on stress assessments of autistic children caring behavior, a project from the Ministry of Health of the Republic of Indonesia in 2019.^[14] The amount of sample used the rule of the thumb in SEM, 9 indicators \times 12 observed variables = 108 parents. Parents were grouped into a controlled group without treatment with 54 people and a treatment group with 54 people, implementing a stress assessment-based coping module. Group determination was carried out randomly among all parents. Data were collected from May to July 2022 using a questionnaire. A structured questionnaire was used to collect the necessary data, consisting of three questionnaires. The stress assessment questionnaire consists of 39 statements including behavioral, attitudinal, emotional, and physiological aspects,^[10] with each statement rated on a Likert scale (1 = never to 5 = very often) – mild stress score; less than 60% ($\leq 23/39$), moderate stress; 61–79% (24–30/39), severe stress; above 80% ($>30/39$). Reliability and validity values measured by Cronbach's alpha coefficient for all items exceed 0.05. The family coping questionnaire includes problem-focused coping and emotional-focused coping and behavior of autistic children caring. The family coping questionnaire consists of 25 statements including problem-focused coping and emotional-focused coping,^[11] with each statement rated on a Likert scale (1 = never to 3 = always) – scores less than 60% ($<15/25$), sufficient; 61–79% (16–19/25), good; above 80% ($>19/25$). Reliability and validity values measured by Cronbach's alpha coefficient for all items exceed 0.05. The behavior questionnaire for caring for autistic children consists of 22 statements including social interactions treatment, communication, cognitive abilities, behavior patterns, and activities,^[12] with each statement rated on a Likert scale (1 = never to 3 = always) – scores less than 60% ($<13/22$), sufficient; 61–79% (14–17/22), good; above 80% ($>17/22$). Reliability and validity values measured by Cronbach's alpha coefficient for all items exceed 0.05. The data were tested by the two-way variants analysis using the Wilcoxon signed ranks tests and the difference test between groups using the Mann–Whitney U-test.^[15]

Ethical considerations

Permission to conduct research was obtained from the Surabaya Ministry of Health Health Polytechnic (ethical certificate: No. EA/1336/KEPK-Poltekkes_Sby/V/2022), and written consent was obtained from parents of school-aged autistic children who agreed to participate in this research. Participants were informed that their participation was voluntary and could withdraw from the

study at any time and were assured that their responses were confidential.

Results

The results of the study on participant demographic data; 89% were female, 57% were aged 40-50 years, 61% had college education and 58% were housewives [Table 1]. The difference test between samples in the controlled group shows that there are any significant differences in family coping ($Z = 0.13$, $p > 0.05$) and ability to care school-aged autistic children ($Z = 0.08$, $p > 0.05$) [Table 2]. The difference test between samples in the treatment group shows that there are significant differences family coping ($Z = 5.04$, $p < 0.05$) and ability to care school-age children ($Z = 5.08$, $p < 0.05$) [Table 3]. difference test between the control and treatment groups shows that there are significant differences in family coping ($Z = 5.75$, $p < 0.05$) and the ability to care school-age children ($Z = 7.00$, $p < 0.05$) [Table 4].

Discussion

Currently, the existence of autistic children with limited social behavior, language decline, and the negative impact of their existence are a major stress trigger for families, which can result in the emergence of maladaptive family coping. Adaptive family coping is needed for being able to care with love and full attention, so it optimizes development capabilities and no failure in the development of school-aged autistic children. Research findings showed that families with mild or no stress due to the presence of autistic children have a good coping and a good behavior of caring for autistic children.

In quasi-experimental research on parents without treatment, significant differences in family coping ($Z = -0.13$, $p < 0.05$) and the ability of care for school-age autistic children ($Z = -0.086$, $p < 0.05$) cannot be found. Parents of the control group without treatment had less understanding that the abilities of autistic children were more difficult to be stimulated; stimulation must be structured and takes longer than for normal children, and they are less able to reflect on the presence of autistic children at home, so reactions arise that can be caused by various demands, important challenges, threats, and when one must try to overcome unrealistic expectations from the environment.^[16] This disability making the presence of an autistic child becomes a major stress trigger for the family, supported by the results of mothers who have autistic children experiencing a higher level of stress than those who have no autistic children.^[17] Family major stress can result in care patterns tending to be more authoritarian and permissive and can lead to maladaptive family coping. Families with a bad coping pattern or maladaptive develop a prolonged feeling of sadness, guilty feelings, or blaming among family members, and feelings of hatred toward autistic children result in low affection and attention,

decreasing the behavior of caring autistic children. This is according to research stating that mothers who have autistic children in this study have higher levels of parenting stress, especially in the parental aspect, where they feel having a lack of ability to care for their children.^[5]

In the treatment group, significant differences in family coping ($Z = -5.04$, $p < 0.05$) and the ability of caring for school-aged children ($Z = -5.08$, $p < 0.05$) were found. The

Table 1: Demographic characteristics of control and treatment groups (n=108)

Indicator	Category	n
Gender	Woman	96 (89%)
	Man	12 (11%)
Age	<40 years old	40 (37%)
	40–50 years	62 (57%)
	>50 years	6 (6%)
Education	Intermediate	42 (39%)
	College	66 (61%)
Work	Housewife	62 (58%)
	Private	35 (32%)
	civil servant	11 (10%)
Total		108 (100)

Table 2: Two-way difference test on the assessment of stress, coping, and behavior of caring for autistic children between samples in the control group (n=54)

	Assessment stress	Coping Family	Behavior caring
Mean (SD)	22 (18.96)	23 (9.70)	21 (8.16)
Z	0.59	0.13	0.08
p*	0.551	0.892	0.931

*The results of the Wilcoxon Signed Ranks Test

Table 3: Two-way difference test on assessments of stress, coping, and behavior of caring for autistic children between samples in the treatment group (n=54)

	Assessment stress	Coping Family	Behavior caring
Mean (SD)	15 (4.10)	24 (10.67)	21 (8.16)
Z	5.67	5.04	5.08
p*	0.001	0.001	0.001

*The results of the Wilcoxon Signed Ranks Test

Table 4: Test of differences in assessments of stress, coping, and behavior in caring for autistic children between the control group and the treatment group (n=108)

	Assessment stress	Coping Family	Behavior caring
Mean (SD)	18 (11.50)	24 (10.18)	21 (8.16)
Z	8.858	5.751	7.003
p*	0.001	0.001	0.001

*The results of the Mann–Whitney U test

increased ability becomes a stressor for parents, family support for parents, togetherness of parents, and families facing stressors of the presence of an autistic child; the stressor pressure of an autistic child resulting in feelings, bad thoughts, and parental activities turns parents' major stress into mild stress or even no stress, supported by Gruhn distraction and disengagement coping or emotion-focused coping, which have a significant positive effect on pressure only when the child's maladaptive behavior is less severe, while it has no effect on the pressure when the behavior gets worse.^[18] A positive view of parents or not being stressed makes parents control themselves and makes themselves as an important psychological resource in creating an adaptive coping.^[19] Families with good or adaptive coping models will be able to increase togetherness among family members getting closer, maintain and manage positive stress levels, and reduce physiological and psychological reactions of themselves and family members due to stressors of their involvement in caring for autistic children,^[20] supported by Choi, that is, applying problem-focused coping can decrease the degree of mother parenting stress.^[21]

The research has limitations. Differences in educational background and parental understanding ability factors exist in individual responses to the three questionnaires. Access to treatment is only given to one group, and both groups must fill out a questionnaire. The research target is limited to urban areas, and not all parents of autistic children are accessible. Access to the normal sample was limited because they did not have autistic children attending the therapy center.

To equalize parental abilities due to differences in educational levels, before starting the study, all students' parents were explained about the procedures and aims of the study, and then consent was taken from all participants. Parents were informed that their participation was voluntary and could withdraw from the study at any time and were assured that their responses were confidential. Access limitations can be eliminated by dividing the research site into four areas so that we get the central city and outskirts (describing rural communities). Determination of the therapy center as the research location based on the four regions and group members in the study was carried out randomly.

Conclusion

The application of the family coping model influences the behavior of caring for autistic children. Parents who are not stressed about the existence of an autistic child can control themselves and make themselves an important psychological resource in creating adaptive coping so that they can manage social support, especially from family and professional staff for getting comfort, attention, or assistance improving the caring behavior of autistic children. Further research with the support of the Surabaya Health Polytechnic will add a psychosocial response based on the complete family coping model that can improve behavior in caring for autistic children.

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Conflicts of interest

Nothing to declare.

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