Original Article

# Family Coping Model Based on Psychosocial Responses to the Ability to Care for School-Age Autistic Children

**Hasyim Asari[1], Suriana[1], Hilmi Yumni[2]**

*[1]Department of Pediatric Nursing, Health Polytechnic of the Ministry of Health, Surabaya, East Java, Indonesia, [2]Department of Maternity Nursing, Health Polytechnic of the Ministry of Health, Surabaya, East Java, Indonesia*

## Abstract

**Introduction:** The increasing prevalence of autism was a burden, especially for families and made them feeling stressed and ashamed of the negative stigma from the social environment, so that psychosocial response of the family critical and maladaptive coping was created. To build a family management model based on psychosocial responses to the family's ability of caring for school-age autistic children. **Materials and Methods:** The research design used a quasi-experiment. The population and samples were parents of autistic children, who had attended Surabaya Autism Therapy Center. The determination of the sample sizes used the rule of thumb formula in Structural Equality Modeling (SEM) several 108. The data collection technique used Multi-Stage Sampling. The measuring instrument used a questionnaire. Modeling analysis used Partial Least Squares Structural Equality Modeling (PLS-SEM). **Results:** The results of the prediction test of the model showed R-square = 0.497 (strong). The relevance test of the model prediction showed Q-Square = 0.482 (good). The model accuracy test showed Goodness of Fit (GoF) = 0.376 (large). The test of the influences between variables showed that the social support had a significant impact on psycho-social responses ($p$ = 0.001), the psycho-social response had an important influence on family coping ($p$ = 0.001) and the family coping had a significant impact to the ability to care for autistic children ($p$ = 0.001). **Conclusions:** The family coping model based on psychosocial responses was an appropriate model that had a significant influence on the ability to care for autistic children.

**Keywords:** *Autism, child care ability, family coping, psycho-social response*

## Introduction

The global prevalence of autism in 2022 was 2.3% and increased to 2.8% in 2023.[1] The prevalence of autism in Indonesia in 2021 was recorded at 2.4 million. It increased by 500 children in 2022.[2] Autistic children with various developmental limitations were a problem that had to be faced by families in society. Families were affected by severe and long-term effects due to the presence of autistic children.[3] Families often faced emotional and psychological challenges that could cause psychosocial stress and problems psychosocial, including depression. As a result, families faced various severe difficulties in caring for the needs of their children as well existence feeling pessimistic about time front child.[4]

Families with autistic children sometimes lacked social support, even doing inappropriate things to autistic children such as bullying or mistreating them by their peers so that the autistic child died. The phenomenon was parents with autistic children feeling ashamed and end up abandoning their children or even shackling them.[5] Lack of social support in consequence of the existence of autistic children with limited or even low communication skills, relationships with people and the environment, sensory stimulation, and behavioral development were problems that parents had to face among their society.[6] Some parents who had children with special needs felt pressured and ashamed by the stigma of society, so they tended to hide their child.[7] This condition caused social support in the form of perceptions of comfort, excessive attention, or assistance received by individuals from others since the presence of autistic children became a deficiency for the family.[7] Lack of support could cause psychosocial responses to become critical, resulting in psychosocial problems and psychosocial stress as well as maladaptive coping. Past experiences, perceived



**How to cite this article:** Asari H, Suriana, Yumni H. Family coping model based on psychosocial responses to the ability to care for school-age autistic children. Iran J Nurs Midwifery Res 2026;31:413-7.

**Submitted:** 31-Oct-2023. **Revised:** 03-Jan-2025. **Accepted:** 02-Sep-2025. **Published:** 16-Jun-2026.

***Address for correspondence:***
*Mr. Hasyim Asari, Department of Pediatric Nursing, Health Polytechnic of the Ministry of Health, Surabaya, East Java, Indonesia. E-mail: hasyim@poltekkesdepkes-sby.ac.id*

**Access this article online**

**Website:** https://journals.lww.com/jnmr

**DOI:** 10.4103/ijnmr.ijnmr_340_23

**Quick Response Code:**

social support, and the nature of stressful situations were examples of factors that influenced coping strategies.[8]

Coping strategies that used by mothers who had low-category autistic children were more likely avoidant coping. Avoidant coping was conducted by denying stress cognitively.[9] Such as; parents released emotions due to reducing distress, feelings of anger, or other negative feelings. Another study explained that the coping strategy that was mostly used by mothers who had children with special needs was problem-focused engagement.[10] In accordance with research, a higher level of stress had been experienced by parents who were involved using strategies that more focus on emotions than problems.[11] Therefore, families tended to cope better while following strategies that focusing on problems than those who focusing on emotions. If the family's coping was maladaptive, a feeling of sadness would arise.[12] which was prolonged, feelings of guilt and mutual blame between family members, or feelings of hatred towards autistic children in providing care for school-age autistic children became inappropriate. The ability of caring for school-age autistic children without considering the characteristics and abilities of autistic children could cause the failure of growth and the development of physique, psychology, and also mental which resulted in the loss of the nation's next generation since autistic children played a role in determining the future of the nation.[13] The family with coping adaptive would be able to increase feeling of love and optimal attention to autistic children of school age. Therefore, they could optimize the abilities development of autistic children.[14]

The Efforts of achieving an adaptive coping model for families could be made by developing a family coping model based on psychosocial stress to improve the family abilities of caring for autistic children.[15] This family coping model had not been widely studied in Indonesia. Most of the previous studies were only on stress and coping strategies, the purpose of which was to describe the stress and coping strategies of parents with autistic children. Therefore, the researcher wanted Parenting Stress Index Short Form to conduct a study aimed to build a family management model based on psychosocial responses to the family's ability of caring for school-age autistic children.

## Materials and Methods

The research conducted in 2022 and design was a quasi-experiment. The population and sample were parents of autistic children who had attended Surabaya Autism Therapy Center. The determination of the sample size used the rule of thumb formula in Structural Equality Modeling (SEM), namely 9 indicators × 12 observed variables = 108 parents of autistic children.[17] The data collection technique used Multi-Stage Sampling. The data collection process was; first, it was conducted by grouping based on four autism center areas in Surabaya, and second, parents of autistic children randomly selected it. Parents of autistic children outside the group were not included as participants. Before the study, parents were explained about the procedures and objectives of the study, and consent was taken for those who were not willing to be excluded. The measurement instrument used a questionnaire. The social support questionnaire was adapted from the Medical Outcome Study; Social Support Survey Instrument (MOS-MSSS) consisting of 20 statement items, each statement consisting of 4 answer choices, namely never, rarely, often, and always. The score ranges between 20 and 80. The psycho-social response questionnaire was adapted from the Impact of Event Scale-Revised (IES-R), consisting of 22 items. The total IES-R score was divided into 0–23 (normal), 24–32 (mild), 33–36 (moderate) >37 (severe).[16] The behavioral questionnaire for caring autistic children consisted of 22 statements including social interaction, care, communication, cognitive abilities, behavior patterns, and activities, with each statement was assessed on a Likert scale (1 = never to 3 = always)—score less than 60% (<13/22), sufficient; 61%–79% (14–17/22), good; above 80% (>17/22). Modeling analysis used partial Least Squares Structural Equality Modeling (PLS-SEM). The study was conducted from May to September 2023. The data were analyzed using SPSS software, $p < 0.05$ is considered statistically significant.[17]

### Ethical considerations

The permission of conducting the study was obtained from the Health Polytechnic of the Ministry of Health of Surabaya (ethical certificate: No. EA/1336/KEPK-Poltekkes_Sby/V/2022) and written consent was obtained from parents of school-age autistic children who agreed to participate in the study. 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 study resulted on participant demographic data; 73% ($n$ = 108) were female, 78% ($n$ = 108) had intermediate and 58% ($n$ = 108) were housewives [Table 1]. The results Validity test resulted in construction and composite reliability social support, psycho-social response, family coping construct, and autism care behavior with Cronbach's alpha value >0.5 with the Average Variance Extracted value (AVE) >0.5 and composite reliability >0.7.

The study that resulted on participants of the initial and final inner model structural tests showed a significant relationship between the social support variable and psycho-social response ($p$ = 0.001), psycho-social response with family coping ($p$ = 0.001), and family coping with the ability to care for autistic children [Figures 1 and 2]. The results of the prediction test of the determinant coefficient on the endogenous construct of the model obtained

R-square = 0.497 (strong). The relevance test of the model prediction obtained Q-Square = 0.482 (good). The model accuracy test obtained Goodness of Fit (GoF) = 0.376 (large) [Table 2]. The test of the influence between variables obtained that the social support variable had a significant impact on psycho-social responses ($p$ = 0.001), the psycho-social response variable had an important influence on family coping ($p$ = 0.001) and the family coping variable had a significant impact on the ability to care for autistic children ($p$ = 0.001) [Tables 3 and 4].

**Table 1: Characteristics of parents of autistic children at the Surabaya autism therapy center, ($n$=108)**

| Indicator | Category | *n* |
|---|---|---|
| Gender | Female | 79 (73%) |
| | Male | 29 (27%) |
| Education | Elementary | 10 (9%) |
| | Intermediate | 84 (78%) |
| | College | 14 (13%) |
| Work | Housewife | 62 (58%) |
| | Private | 33 (31%) |
| | Civil servant | 12 (11%) |
| Total | | 108 (100) |

The results of the study on participant demographic data; 73% were female, 78% had intermediate and 58% were housewives

**Table 2: Test of construct validity, variable reliability, and Goodness of Fit (GoF) ($n$=108)**

| Test | Psychosocial response | Coping | Caring behavior | GoF |
|---|---|---|---|---|
| Cronbach's alpha | 1,000 | 1,000 | 1,000 | 0.376 |
| Composite reliability | 1,000 | 1,000 | 1,000 | |
| Average variance extracted | 1,000 | 1,000 | 1,000 | |
| R-square | 0.135 | 0.166 | 0.497 | |
| Q-square | 0.110 | 0.143 | 0.482 | |

AVE, R-Square, GoF* are calculated with SEM-PLS.
PLS-SEM=Partial Least Squares Structural Equality Modeling

## Discussion

This study aimed to build a family coping model based on psycho-social responses to family coping abilities that caring for school-age autistic children. This family coping model had not been widely studied in Indonesia. Most of the previous studies were about stress and stress coping strategies. The purpose described the stress and coping strategies of parents with autistic children.[18] The findings of the family coping model study, which was built based on psycho-social responses, were obtained from good social support. Parents who had autistic children felt stressed and ashamed due to the stigma from the social environment.[7] The condition of having autistic children among the family required social support and caused a lack of family and psycho-social problems. This was a source of psycho-social stress that caused maladaptive coping for the family.[8]

Good social support and psycho-social responses created adaptive family coping. Therefore, they were able to care for their loved children with full attention and love. Low social support occurred since the existence of autistic children was considered by the social environment as problem. This problem should be faced by parents that caused feeling confused, Low self-esteem of parents, anxiety, incompetence, and inability making contact with their children, and social and intellectual guidance of children.[19] Psycho-social problems could become a crisis when it was not any support or insufficient support: 1) when the child was diagnosed, conflict; about differences of opinion about children, treatment, financial problems,

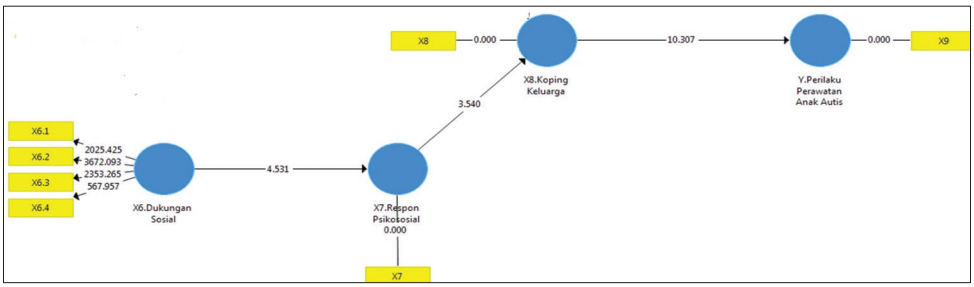


**Figure 1: Initial inner model test diagram**

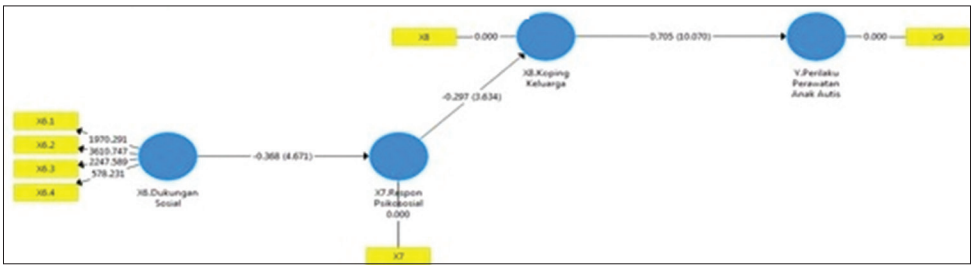


**Figure 2: Final inner model test diagram**

**Table 3: Test of the influence between variables of the initial model on social support, family coping, and behavior in caring for autistic children (*n*=108)**

| | Social support with psychosocial responses | Psychosocial responses with coping | Coping with caring behavior |
|---|---|---|---|
| *t* | 4,531 | 3,540 | 10,307 |
| *P*s | 0.001 | 0.001 | 0.001 |

*p** is calculated by *t*-test

**Table 4: Test of the influence between variables of the final model on social support, family coping, and behavior in caring for autistic children (*n*=108)**

| | Social support with psychosocial responses | Psychosocial responses with coping | Coping with caring behavior |
|---|---|---|---|
| *t* | 4,671 | 3,634 | 10,070 |
| *P*s | 0.001 | 0.001 | 0.001 |

*p** is calculated by *t*-test

and blaming each other between husband and wife; and 2) facing the extended family and society, conflict; shame and stress towards the surrounding environment and wrong treatment from society so that the family bear a heavier burden.[20] Supported by the results of several studies, parents who had children with special needs had felt pressured and ashamed. As a result, they tended to hide their children.[8] This condition generated various psycho-social problems including depression that started from stress, anxiety, and angry behavior since they had to face various severe difficulties in caring for their children as well as feeling pessimistic about the future of autistic children.[21]

Research findings stated that excellent social support had made excellent psycho-social responses. According to the research, past experiences, perceived social support, and the nature of stressful situations were factors that had influenced coping strategies.[4] Supported by research, it stated that using the nature of stressful situations could determine the type of strategy that overcome it, namely individuals tend to use emotion-focused strategies in situations where they were unable to make direct efforts to deal with the situation such as health problems. They tended to use problem-focused strategies while they could handle and control, such as family conflict.[8]

Research findings indicated that inadequate psycho-social responses had created maladaptive family coping. Families with maladaptive coping could experience feelings of prolonged sadness and guilt. Blaming between family members, and hatred towards autistic children had resulted in low affection and attention and decreases the behavior of caring for autistic children. According to the results of the study, it stated that mothers who had autistic children in this study had achieved high levels of parenting stress, especially in the parental aspect where there was a feeling of inadequacy in caring for children.[18]

The family coping model that had been built based on psycho-social responses was appropriate for making good family coping (adaptive) and increasing the ability to care for autistic children. According to research, A good family psychosocial response would have a positive view of parents or would not cause stress for parents. They were going to control themselves. They also made themselves as an important psychological resource in creating adaptive coping.[8] Families with adaptive coping would be able to increase togetherness between family members becoming closer, maintain and manage levels of positive stress and reduce physiological and psychological reactions of themselves and family members due to stressors in their involvement in caring for autistic children.[22] According to the research, distraction and disengagement coping or emotion-focused coping had provided a significant positive effect only on stress when the child's maladaptive behavior was not too severe. Whereas, it had not any effect on stress when problem behavior was more severe. The use of problem-focused coping was going to reduce the mother's parenting stress level.[23]

Limitations of the study were differences in educational background and parents' understanding factors appear in individual responses to the three questionnaires. Access to the treatment was only given to one group. Both groups should fill out the questionnaire. The research target was limited to urban areas and not all parents of autistic children could access it. Access to normal samples was limited because they did not have autistic children attending therapy centers. To equalize the ability of parents due to differences in education levels, before starting the study, all parents of students were explained about the procedures and objectives 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. The participants were assured that their responses were confidential. To eliminate access limitations, the research location was divided into four areas so that the central city and suburban areas (representing rural communities) were obtained.

## Conclusion

The psycho-social response-based family coping model was an appropriate model. It had a significant influence on the ability to care for autistic children. Adaptive coping enabled families to manage social support due to obtaining comfort, attention, or assistance in improving parenting behavior for autistic children.

### Acknowledgments

We thank all parents for participating in this study and the Health Polytechnic of the Ministry of Health Surabaya, Indonesia for their cooperation in data collection.

## Financial support and sponsorship

Nil.

## Conflicts of interest

Nothing to declare.

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