



Literature Review

## THE INTERVENTION TO ENHANCE THE COPING OF PARENTS OF CHILDREN WITH AUTISM: A LITERATURE REVIEW

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### ABSTRACT

**Introduction:** Parents with autism spectrum disorder children need for more space up her time to treat their children right, and experienced stress because of their autism spectrum disorder children. Children with autism spectrum disorder have a different parenting program with normal children because of disruption verbal, nonverbal, and social interaction growth. This study aims to explain the interventions to enhance the coping of parents of children with autism.

**Method:** This study was a literature review. The literature was searched using electronic database: Scopus, CINAHL, Science Direct, Sage, Google Scholar with inclusion criteria include parents of children with Autism Spectrum Disorder, articles published in 2011-2021 using experimental studies in English and Indonesian. Ten articles obtained for review.

**Results:** Ten articles that fulfilled the inclusion criteria were chosen to be analyzed. From ten articles there are divided into two interventions on it, Cognitive Based Intervention which are Parent Education Program, Coping Effectiveness Training, Mindfulness-Based Interventions, Problem-Solving Skills Training, and Psychological Based Intervention which are Virtual Resilience Intervention.

**Conclusion:** This research shows that some interventions or programs that have been examined effectively can increase coping at parents who has autism spectrum disorder children. The intervention that is considered the most effective and often used is the parent education program.

### Keywords

Intervention; coping; parents with autism spectrum children; literature review

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## 1. INTRODUCTION

Autism spectrum disorder is a neurodevelopmental disorder characterized by deficits in social communication and the presence of restricted interests and repetitive behaviors (Hodges et al., 2000). Common disorders of autism other than disorders in social cognition, namely the emergence of repetitive behavior and odds behavior and are rarely found among children his age. The inhibition of the developmental process in children with autism affects their independence. Only a few children with

autism develop to be able to live a normal social life until they can work (Sitimin et al., 2017). Parents who raise children with autism also face extreme difficulties in dealing with children's behavior, teaching basic life skills, protecting children from harm, and preparing children for life in adulthood (Manning, M. M., Wainwright, L., & Bennett, 2011; Wang et al., 2018).

Children with autism certainly has a significant impact on a family. Daily life in the household will change, such as children with autism will need more help so that routines in the household are neglected,

or even parents' careers will be stopped to take care of their children. The thing that most often causes stress to parents is delays or limitations in communication. Many challenges that families must face and the responsibilities of caring for a child with autism can be stressful. This stress is triggered by parental concerns about their ability to cope with their child's behavior problems, high fatigue during parenting, worries about the child's future and child's independence, hampered careers, and financial problems that have not been fulfilled.

Parents with autistic children face many difficulties every day, and coping strategies are one of the variables that can protect them from emotional disturbances. Prior study (Iadarola et al., 2019; Ilias et al., 2018) found that parents with autism children could experience stress due to interference with family functioning, misperceptions of ASD, cultural factor, and service navigation difficulties. Considering the need for therapy and treatment of children with autism, which is quite expensive, also not to mention the views of others on the child's condition (Koydemir, S., & Tosun, 2011).

Immediate intervention for parents of children with autism is essential to avoid the negative effects of stress. These negative impacts can lead to suboptimal care for children with autism. Some parents can be emotionally overstretched, limiting their functioning in various aspects of life. Meanwhile, for other parents, the impact of high-stress levels in raising children with autism can cause depression (Hidayah, R., Yusuf, A., & Fitriyasaki, 2017).

From the description above, it is necessary to review to find effective intervention from several previous studies that aim to improve current parental coping in the care of children with autism.

## 2. METHODS

This study uses a literature review method. The literature search was carried out in three stages, namely: planning, conducting, and reporting.

The first stage that researchers do is planning. In this stage, researchers conduct Research Questions that lead to the topic to be studied. In this study, the question posed was what intervention that effective to increase coping and decrease stress in parents with Autism Syndrome Disorder children.

The second stage is conducting, which is the stage of implementation. Starting from the determination of literature search keywords. The literature search was conducted using English keywords (Interventions OR programs AND Parents AND Coping OR coping behavior AND Autism Spectrum Disorders), Bahasa Indonesia keywords (Intervensi; program, Orang tua, Koping; perilaku koping, Gangguan spektrum autisme) and BOOLEAN

operator (AND, OR NOT, or AND NOT). A literature search was conducted in February 2021.

This study uses academic databases of high and medium reputation, including SCOPUS, CINAHL, Science Direct, SAGE and Google Scholar with inclusion criteria of healthy parents who have children with Autism Spectrum Disorder, articles published in 2011-2021, and studies published analyzed the intervention using an experimental study using English and Bahasa Indonesia. Exclusion criteria are parents with unhealthy conditions who have children with autism spectrum disorder and studies with a narrative review design.

The selection process was conducted on 988 articles obtained from all databases. Duplicate removal was done with Mendeley so that the remaining 937 articles for further identification of titles and abstract screening so that 97 articles were obtained. From the article that has passed the abstract selection then made an exception to the article that does not meet the criteria of inclusion so that 10 articles are reviewed. Quality assessment is carried out based on The Joanna Briggs Institute (JBI) Critical Appraisal on the inclusion and exclusion criteria of 10 articles that can be used in the literature review. Furthermore, researcher interprets the data and develops an analysis of the findings obtained.

## 3. RESULTS

The results of literature searches that have been analyzed and determined in the literature review are as follows:

Table 1 Study Characteristics

Category	Total (N)	Percentage (%)
<b>Total</b>	<b>10</b>	<b>100</b>
<b>Database</b>		
Scopus	4	40
CINAHL	2	20
Science Direct	1	10
SAGE	1	10
Google Scholar	2	20
Indonesia		
<b>Total</b>	<b>10</b>	<b>100</b>
<b>Research Design</b>		
Randomized	6	60
Controlled Trials	4	40
Quasy-Experimental Studies		
<b>Total</b>	<b>10</b>	<b>100</b>

The articles search process found that interventions that can improve coping in parents who have children with autism spectrum disorder (ASD), including:

### **Parent Education Program**

Research by Al-Khalaf et al. (2014) involved 12 pairs of parents of children with autism in Jordan. This study uses a Quasi-Experimental Studies research design. Data collection was carried out in three stages: pre-intervention interviews, educational programs, and post-intervention interviews conducted one week after the education was given. After a four-week parent education program, mothers reported a statistically significant reduction in stress levels, improved coping skills, and increased mother-child interactions. Compared to fathers, mothers' stress levels were significantly higher, and their coping skills were much lower. The results have valuable implications for interventions for families with children with ASD living in Jordan or other Arab countries.

Research conducted by (Chiang, 2014) involved 11 parents of children with autism who were given an educational program for ten weeks using a pre-post group design. A total of ten topics were developed based on the results of the parental interest survey, including the understanding of ASD, special education systems, teaching communication skills, teaching play and social skills, reducing challenging behavior, teaching academic skills, teaching functional skills, opportunities, and outcomes for individuals with ASD, strategies countermeasures, and community resources.

### **Progressive Psychoeducation and Relaxation**

Research conducted by Suharsisti (2018) involved five parents of children with autism at SLB Nur Abadi. The criteria used are HARS (Hamilton Anxiety Rating Scale), where the criteria include 14 statements of stress symptoms to see that knowledge about autism is measured using an autism knowledge scale consisting of 16 statements. This study uses an experimental research design. Stress levels in subjects decreased because the intervention targeted specific types and sources of stressors that cause problems, such as psychoeducation about autism to increase knowledge about autism and progressive relaxation to reduce physical responses to stress. The advantage of psychoeducation is the flexibility of the model so that it can be adapted to individual situations and conditions.

### **Parent Mentorship Program**

Research conducted by (Moody, E. J., Kaiser, K., Sharp, D., Kubicek, L. F., Rigles, B., Davis, J., McSwegin, S., D'Abreu, L. C., & Rosenberg, 2019) involved 33 parents who were given the intervention and 34 parents who were not given the intervention as a comparison. The intervention consisted of developing an individual action plan and training on the navigation service system immediately upon entry into the program, followed by a monthly check-in by a trained parent mentor for six months. The intention-to-treat analysis examined the Colorado Parent Mentoring Program (CPM) impact on family

quality of life, family functioning, service utilization, and program acceptance and satisfaction. The design of this study used a Randomized Control Trial.

### **Psychoeducation**

Research conducted by (Hemdi, A., & Daley, 2017) involving 62 mothers in the Kingdom of Saudi Arabia : session 1 to inform parents about the etiology of ASD, session 2 to target stress in mothers and how they can approach different stressful situations, session 3 to child behavior problems to help mothers cope with the initial stressors of having a child with ASD, and session 5 to inform mothers about available resources. The intervention material was developed in a booklet format which was divided into five parts. Interventions in line with fundamental principles and recommended practice guidelines, WhatsApp is a free mobile messaging application where people can exchange private or group messages also visual and audio media.

### **Parenting Skills Training**

Research conducted by (Hidayati, 2013) involved 20 parents of children with autism divided into control and experimental groups. The "Pengasuh Ibu Cerdas" training was provided in 8 sessions in 2 meetings during the week. Each meeting lasted approximately 240 minutes. The intervention was given to research subjects in the experimental group. The research material consists of understanding material about children with autism, the material on the dimensions of parenting (care, control, and communication), and material on recognizing stress and how to manage stress, ending with an action plan. The results of this study reduce the stress level of parenting of autistic children.

### **Coping Effectiveness Training (CET)**

The study of (Haakonsen Smith, C., Turbitt, E., Muschelli, J., Leonard, L., Lewis, K. L., Freedman, B., Muratori, M., & Biesecker, 2018) conducted a CET trial on 22 parents of children with autism. This intervention helped participants match problem-solving strategies with stress rated as controllable coping strategies and focusing on emotions with pressure placed as uncontrollable. The result of this study is that the CET intervention is feasible to apply.

### **Mindfulness-Based Interventions (MBI)**

(Rayan, A., & Ahmad, 2016) involved 104 participants in Jordan divided into an experimental group and a control group. The study design used is a Quasy experimental study. The short MBI adaptive intervention was carried out for five weeks. In the first week, psychological education was given about the difficulties experienced by parents and the benefits of mindfulness. In the second week, the trainees' homework was reviewed to acquire new skills and practice. In the third week, parents will get the lesson to read about the knowledge of playing with children and the benefits of mindfulness. In the

fourth week, parents are given lessons to read about eating, observe the child, and then discuss it over the phone. The results showed an increase in the intervention group compared to the control group.

### **Problem-Solving Skills Training**

Research by (Nguyen, C. T., Fairclough, D. L., & Noll, 2016) involved 17 mothers of children with autism. Participants received eight 1-hour problem-solving skills training sessions. They were asked to complete assessments before starting problem-solving skills training (T1), immediately after the intervention (T2), and three months after the intervention or T2 (T3). Outcome measures assess problem-solving skills and effectiveness negatively (i.e., distress). The results show that problem-solving skills training is an effective way to reduce stress on mothers of children who have recently been diagnosed with an autism spectrum disorder.

### **Virtual Resilience Intervention**

Research by (Kuhlthau, K. A., Luberto, C. M., Traeger, L., Millstein, R. A., Perez, G. K., Lindly, O. J., Chad-Friedman, E., Proszynski, J., & Park, 2020) using the Stress Management and Resiliency Training-Relaxation Response Resiliency Program (SMART-3RP) involved 51 participants who have children with autism. The design used is a Randomized Pilot Trial. The intervention was delivered in 8 virtual sessions for 1.5 hours. Mind-body interventions refer to interventions aiming to bring body and mind together to promote health and healing through various practices such as relaxation techniques, mindfulness meditation, and yoga. This intervention promises to increase resilience in a group of older people experiencing high levels of stress and a growing population.

## **4. DISCUSSION**

Efforts that can do made to reduce the psychosocial impact felt by parents of children with autistic disorders are to provide parenting education through psychoeducation to parents. Psychoeducation can do to individuals, families, and groups that focus on educating participants about significant challenges in life, helping participants develop sources of support and social support in facing challenges and developing coping skills. Psychoeducation is considered effective in shaping or changing perceptions and improving cognitive aspects or parents' understanding of strategies for dealing with children with autism disorders to reduce parenting stress. Participation in Parents Education Program may increase feelings of agency and decrease feelings of guilt. For some parents, this alone could reduce stress and strain and boost self-efficacy. The boost in self-efficacy may enhance parents' ability to manage disruptive behaviors (Bradshaw et al., 2018; Fitriyasi et al., 2019).

Based on the findings of this study, parents who get coping effectiveness training feel more confident in their ability to handle problems, resulting in more successful therapy and reduced stress for parents. Self-Efficacy is an important cognitive element which is a belief or expectation about how far a person can perform a behavior in a certain situation. Without Self-Efficacy, a person can become devoid of the desire to do something. This intervention is considered effective because it can increase Coping Self-Efficacy in parents of children with autism. Other study found that Making meaning out of their parenting experience may be the key to improving their coping skills and mothers learned to not avoid stressors, to feel less anxious and depressed in their everyday life, and to find a positive meaning in raising their children with ASD (Iida et al., 2018; Predescu, E., Dobrea, A., Pop, C., Micluția, I., & Șipoș, 2013; Salas, B. L., Rodríguez, V. Y., Urbieta, C. T., & Cuadrado, 2017). Coping strategies were not associated with child age or ability, but were associated with maternal mental health (Adams et al., 2017). This finding showed that mother's mental health will determine the coping strategies used to care for their ASD children.

Parents who have high Mindful Parenting make mothers care for children with full awareness, accept their children's conditions, develop children's abilities and independence, establish good relationships with their children and better recognize their children's competencies and understand children's behavior and parenting. mothers will influence the development of their children. When parents who practice mindful parenting are less consistent in their parenting, they feel unpleasant emotions such as anxiety, anger, upset, and confusion in caring for their children. As a result, this mindful parenting-based intervention can be effective. Other study stated that mindfulness parenting training reduces parental stress (Ghanavaty et al., 2021). Mindful Parenting improved parent-child interactions in mental health settings, changes including increased parental attention, reduced stress and preoccupation, improved executive functioning on the part of the children, and a breaking of the cycle of repeating dysfunctional own upbringing schemes together with increasing self-nourishing attention (Bogels et al., 2013; Cachia et al., 2016).

Resilient parents could respond healthily and productively, as well as cope with and manage the stresses that they confront in everyday life, particularly when it comes to parenting. Being a resilient individual was not only having a positive impact on the parents themselves but can support the optimal development of children's lives and can help children with autism disorders to be able to live independently in the future. Parents' incapacity to attain self-resilience might interfere with their function and role as parents, particularly when it comes to parenting chores. As a result, this study is

considered effective. Augmenting resilience has been evidenced to positively impact cognitive appraisal and self-efficacy in families of autistic children (Kotera et al., 2021).

## 5. CONCLUSION

Several interventions that have shown effective results to improve coping in parents with cognitive-based autism spectrum disorder (ASD) children include educational programs for parents, coping effectiveness training, Mindfulness-Based Interventions, and problem-solving skills training. While the psychological-based intervention is a virtual resilience intervention. This study finding showed that increasing parents' knowledge and coping skill will decrease the level of stress of parents with ASD children.

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Table 2 Articles List that had been reviewed

No	Title	Participants	Findings
1	The Effect of an Education Program for Mothers of Children with Autism Spectrum Disorder in Jordan (Al-Khalaf et al., 2014)	12 pairs of parents of children with autism	The major finding from this study was that mothers reported a high level of stress before the education program and a moderate level of stress at the end of the intervention. There was also a statistically significant increase in mothers coping skills across the intervention.
2	A parent education program for parents of Chinese American children with Autism Spectrum Disorders (ASDs): A pilot study. Chiang (2014)	a 10-week parent education program (including 10-weekly 120-min group sessions).	The findings of this study revealed that after receiving the program, parents of Chinese American children with ASDs showed significant reduction in parenting stress, improvement in parental confidence, and improvement in quality of life in physical health and environment domains.
3	Efektivitas Intervensi Psikoedukasi Autisme Dan Relaksasi Progresif Pada Orangtua Dengan Anak Penyandang Autisme (The Effectiveness of Autism Psychoeducational Interventions and Progressive Relaxation in Parents with Children with Autism) Suharsiti (2018)	5 parents of ASDs children	the average stress after being given psychoeducation and progressive relaxation was effective in reducing the stress of parents of children with autism, namely from the moderate stress category to very light and autism knowledge increased from the moderate to very high category. This study concluded that autism psychoeducation and progressive relaxation were proven to be can reduce stress in parents of children with autism.
4	New study on parent mentoring program for families with ASD children Moody et al. (2019)	a group of parents (N = 33) and compared to a waitlist group (N = 34).	These results suggest that the CPM program was generally acceptable to participants and impacted several areas of family quality of life and family functioning, regardless of the amount of formal services the family received elsewhere. This finding suggests that the CPM intervention helped parents find services that were appropriate to their child and family situation. This suggests that increased autism severity may decrease satisfaction, but when we intervene, we mitigate this relationship. This finding suggests that social support is a protective factor against adverse mental health outcomes regardless of the child's severity symptoms,
5	The Effectiveness of a Psychoeducation Intervention delivered via WhatsApp for mothers of children with Autism Spectrum Disorder (ASD) in the Kingdom of Saudi Arabia: A randomized controlled trial Hemdi & Daley (2017)	Sixty-two mothers (23-52 years) of children (26-78 months). The intervention consisted of one face-to-face session (60 min) and four virtual sessions (30 min each) delivered using WhatsApp.	Although changes in stress and depression were statistically significant, change to clinically normal levels was limited to depression. None of the participants had recovered after the intervention. This intervention with WhatsApp support is beneficial but may need to be augmented with other forms of support for mothers of children with ASD including more condensed sessions on stress and interventions targeting anxiety.

No	Tittle	Participants	Findings
6	Pengaruh Pelatihan "Pengasuhan Ibu Cerdas" Terhadap Stres Pengasuhan Pada Ibu dari Anak Autis (The influence of "pengasuhan Ibu Cerdas" to parenting stress of Mother of Autism Children) Hidayati (2013)	20 mothers of children with autism. The experimental group are 10 people, and the control group are 10 people (waiting list). Training "pengasuhan ibu CERdaS" is given by 7 sessions in the twice meetings.	significant decrease in parenting stress in the experimental group after the training is given.
7	Feasibility of Coping Effectiveness Training for Caregivers of Children with Autism Spectrum Disorder: a Genetic Counseling Intervention Haakonsen Smith et al. (2018)	Caregivers were recruited and randomized into the treatment (n=15) or control (n=13) groups.	The treatment group demonstrated significantly increased CSE from pre-intervention to post-intervention (p=0.02). Between group differences were not significant when comparing the pre-post changes. We provide preliminary evidence that CET may be beneficial to caregivers of children with ASD. The results of this feasibility study support development of a phase II study of this intervention in a larger cohort, aimed to be implemented into a genetic counseling setting
8	Psychological Distress in Jordanian Parents of Children With Autism Spectrum Disorder: The Role of Trait Mindfulness Rayan & Ahmad (2016)	parents of 104 children with ASD	Mindfulness-based intervention may help to reduce psychological distress in Arab parents of children with ASD.
9	Problem-solving skills training for mothers of children recently diagnosed with autism spectrum disorder: A pilot feasibility study Nguyen et al. (2016)	17 mothers completed problem-solving skills training. eight 1-h sessions of problem-solving skills training and were asked to complete assessments prior to beginning problem-solving skills training (T1), immediately after intervention (T2), and 3 months after T2 (T3).	Mothers of children with autism spectrum disorder who completed problem-solving skills training had significant decreases in negative affectivity and increases in problem-solving skills. A comparison to mothers of children with cancer shows that mothers of children with autism spectrum disorder displayed similar levels of depressive symptoms but less negative mood and fewer symptoms of post-traumatic stress.
10	A Virtual Resiliency Intervention for Parents of Children with Autism: A Randomized Pilot Trial Kuhlthau et al. (2020)	51 parenrs. The SMART-3RP is an eight-session mind-body intervention, beginning with 1 intake session, that aims to decrease distress and increase growth enhancement	Findings showed promising feasibility, acceptability, and preliminary efficacy for parents of children with ASD.