

Improved Family Coping Caring for Autistic Disorder Children with Knowledge Education: A Cross-Sectional Study

Peningkatan Koping Keluarga Merawat Anak Autis dengan Edukasi Pengetahuan: Studi Cross-Sectional

Setyoadi Setyoadi ¹, Indri Putri Dwioktavianiani ¹, Ahsan Ahsan ¹

¹ Faculty of Health Sciences, University of Brawijaya, Malang, Indonesia

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Correspondence:

Setyoadi Setyoadi

Faculty of Health Sciences,
University of Brawijaya, Malang,
Indonesia.

Ds. Kalisongo, Kec. Dau,
Kabupaten Malang, Jawa Timur
65151, Indonesia.

Phone: +6281333389075

E-mail: setyoadi@ub.ac.id

Abstract

Introduction: Cognitive, communication, social interaction, behaviour patterns, and activity limitations in autistic children become a source of stress for parents. However, Parents' negative assessment of autistic children leads to maladaptive coping and results in inappropriate parenting behaviour. **Objective:** This study focuses on evaluating parents' knowledge of autistic disorders and their relationship to coping in caring for children with autism. **Method:** A *cross-sectional* study is the design of this study. Involving 22 respondents, namely parents of children with autism whose children attend education at Special Schools (SLB) in Malang City. The data collection instrument was developed using the Knowledge about Childhood Autism Among Health Workers (KCAHW) questionnaire to obtain data on family knowledge variables. Family coping variables using McCubbin's F-COPES questionnaire. Both questionnaires are tools that have been tested for reliability. Analysts are statisticians using the *Spearman Rank test* with a significance of 5%. **Results:** 64% of Participants had high knowledge of autism, and 14% of parents had maladaptive coping. The statistical test results found that the knowledge level about autism was related to family coping mechanisms in children with autism disorder (p -value 0.003; r 0.599). **Conclusion:** Adaptive coping of families with autistic disorder children increases with good parental knowledge. Therefore, health education about autism and its care is always informed to the public to prevent maladaptive coping in the care of children with autism disorders in the family.

Abstrak

Latar belakang: Keterbatasan kognitif, komunikasi, interaksi sosial, pola perilaku, dan aktivitas pada anak autis menjadi sumber stres bagi orang tua. Namun, penilaian negatif orang tua terhadap anak autis menyebabkan koping maladaptif dan berdampak pada perilaku pengasuhan yang tidak tepat. **Tujuan:** Penelitian ini berfokus pada evaluasi pengetahuan orang tua tentang gangguan autis dan hubungannya dengan koping dalam merawat anak autisme. **Metode:** Studi *cross sectional* merupakan rancangan penelitian ini. Melibatkan 22 responden, yaitu orang tua dari anak dengan autis yang anaknya mengikuti pendidikan di Sekolah Luar Biasa (SLB) di Kota Malang. Instrumen pengumpulan data dikembangkan berdasarkan kuesioner Knowledge about Childhood Autism Among Health Workers (KCAHW) untuk memperoleh data variabel pengetahuan keluarga. Variabel koping keluarga menggunakan kuisisioner F-COPES McCubbin. Kedua kuisisioner tersebut merupakan alat yang sudah diuji reliabilitasnya. Analisis statistik menggunakan *Rank Spearman test* dengan signifikansi 5%. **Hasil:** Partisipasi sebanyak 64% memiliki pengetahuan yang tinggi tentang gangguan autis dan masih terdapat orang tua yang memiliki koping maladaptif 14%. Hasil uji statistik menemukan bahwa tingkat pengetahuan tentang autisme berhubungan dengan mekanisme koping keluarga pada anak dengan gangguan autisme (p -value 0,003; r 0,599). **Simpulan:** Koping adaptif keluarga yang memiliki anak gangguan autis meningkat dengan pengetahuan orang tua yang baik. Edukasi tentang autisme dan perawatannya selalu diinformasikan kepada masyarakat untuk mencegah koping maladaptif dalam perawatan anak dengan gangguan autisme di keluarga.



Background

Autism is a disorder in the development of communication and social interaction, and it is difficult to observe and process information (Centers for Disease Control and Prevention, 2022a).

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Children with autism can be hampered in education and social relations. This disorder can be seen by the family and is recognized or diagnosed at 18 months to 3 years; the disorder can occur in all social statuses, races, and ethnic groups (Centers for Disease Control and Prevention, 2022b). based on data released by the Indonesian government through the Central Statistics Agency, there are currently around 270.2 million in Indonesia, with a growth ratio of around 3.2 million children with autism (Badan Pusat Statistik, 2020). The Special School Statistical Data Center recorded the number of autistic students in Indonesia in 2019 as many as 144,102 students (Sukatin et al., 2022).

Normal conditions are not necessarily owned by every individual when born. Some of them have limitations, both physical and psychological, that they have from birth. Children with autistic disorders are one example that can be found in various places (Onaolapo & Onaolapo, 2017). Autism is still a concern in the world of health. There are still many parents who do not understand well how to deal with autistic children, and not necessarily all parents can accept the condition of their children who have autism (Hosseinpour et al., 2022). Parents who have autistic children will experience internal stress and confusion; how should parents deal with children who have autism, and how should they communicate with autistic children because they communicate non-verbally and the emotions of autistic children are unstable, and they like to get angry (Kalalo & Setiawati, 2020). Most parents experience frustration with having autistic children because they need long-term care, and caring for autistic children can be a source of stress compared to caring for children with chronic illnesses (Miranda et al., 2019). Many parents of autistic children are hospitalized because they experience symptoms of mental disorders such as depression, bipolar disorder, obsessive-compulsive disorder, and anxiety disorders (Karpinski et al., 2018). The reason families experience stress is that autistic children have symptoms of severe anxiety, mood disorders, echolalia, difficulty adapting, and speechlessness (Yolanda et al., 2016).

Someone experiencing stress will need a coping mechanism to reduce the stress (Dijkstra & Homan, 2016). Coping mechanisms are efforts to overcome and reduce stress, including direct problem-solving efforts and ego-defence mechanisms used to protect oneself (Maryam, 2017). When a family finds out that their favourite child has a disorder, it will try to find ways to overcome the disturbance experienced by the child. Research conducted regarding family coping mechanisms in children with autism says that the coping used is adaptive (Al-Oran et al., 2022). The situation of children who have autism does not make the family despair. However, it makes the family learn about the child's condition and be strong in facing the reality of their child's condition, seek information in dealing with children with autism, and draw closer to God (Yaacob et al., 2022). Parents who are more mature and take longer to care for autistic children use more adaptive coping (Higgins et al., 2023).

There have been many studies examining knowledge and attitudes towards autistic children among different populations that are either directly or indirectly involved in caring for autistic children in the family (Kaman et al., 2023). A study in Indonesia has shown families and healthcare providers to have good knowledge and attitudes towards autism, but some studies indicate an inadequate level of knowledge that needs to be improved (Daulay, 2020; Asari et al., 2023). In addition, two local studies have demonstrated varying levels of knowledge among the general public (Inayah, 2023; Sutinah, 2016). In several related studies, several studies have highlighted related factors that significantly influence parents' knowledge and attitudes towards autistic children (Hassan & Inam, 2013; Kishimoto et al., 2023). Maternal age, maternal depression, and the child's position among siblings have been shown to have a significant influence on parental attitudes,

whereas other studies have found that highly educated parents have positive attitudes toward autism (Omiya et al., 2020; Arakelyan et al., 2019; Suyami et al., 2020).

The general population may not be aware of autism. This is reflected in a local study that shows that knowledge about autism is still low even though good attitudes are prevalent (Yusuf et al., 2019). The level of knowledge about autism in our setting is still lacking. Thus, because of the varying levels of knowledge worldwide, assessing this domain among parents in our setting was essential. Because parents are directly involved in caring for autistic children, we hypothesized that their knowledge would be perceived as good. By identifying their level of knowledge, action can be taken to strengthen the role of the family in supporting the daily life of autistic children. Autistic children need help from their parents to improve their life, communication and interaction skills. Parents with good knowledge will be more successful in their role in productive and positive interventions for children with autism (Hosseinpour et al., 2022). The implications of this study contribute that not every parent who has children with autism can seek literacy and adapt to care for their children well. Therefore, education by essential health workers is always informed through social media or direct education to parents.

Methods

The research design used in this study is an analytic observational approach with a cross-sectional study. The study design was used to prove the relationship between the level of knowledge about autism disorder and family coping. The research location is in the inclusive school (School for Special) Autism River Kids Malang City. The research was conducted for four weeks, from February to March 2020.

This study's population is all parents with autistic children who are studying at the River Kids inclusive school in Malang City, totalling 59 people. In contrast, the sample of this study is a portion of the population taken by a consecutive sampling technique with the inclusion criteria of fathers or mothers who accompany them to school, are willing to be respondents, and have one autistic child. The age of an autistic child is more than five years. The sample size formula used is the Slovin formula after calculating 22 parents.

The instrument used to measure family knowledge about autism was developed by researchers based on the Knowledge about Childhood Autism Among Health Workers (KCAHW) questionnaire, which consists of 4 domains namely; domain one is about social interaction disorder, which consists of 8 questions items, domain 2 is about communication disorders and language development which consists of 1 question item, domain three is about obsessions and compulsive behaviour patterns which consist of 4 question items, and domain 4 is about disorders and comorbid consisting of 6 question items. The knowledge questionnaire has three answer choices, namely, 0=don't know, 1=yes, and 0=no. The KCAHW questionnaire is reliable for measuring knowledge of autism disorders in children with Cronbach's alpha test results = 0.97 (Bakare, 2008). The instrument for measuring family coping uses the F-COPES questionnaire from McCubbin, which consists of four domains, namely, social support, spiritual support, family support, and acceptance of problems from 30 statement items with answer choices 1=Strongly Disagree, 2=Disagree, 3=Neutral, 4=Agree, 5=Strongly Agree. The f-COPES questionnaire is well known for its reliability tests ranging from 0.78 to 0.95 (Allen & Marshall, 2010).

The research data were analyzed using the statistical parametric rank Spearman test because the variable scale used was intervals with a significance value of 5% using the SPSS version 16 tool. The data from the research results had also been tested for normality using the Kolmogorov-Smirnov

test, which showed that the data were normally distributed and obtained a p-value of 0.07. This research has passed the research ethics committee of the Faculty of Medicine, University of Brawijaya, with number 55/EC/KEPK-S1-PSIK/03/2020. The research site consented to data collection, and each respondent approved informed consent before filling out the research questionnaire.

Results

Sociodemographics of Respondents

Table 1 found that more than half of parents with autistic children aged 31-40 years fall into the category of parents with mature age who have maturity in making decisions, education level most of them are college graduates or bachelors indicating parents with higher education. Higher education institutions can provide educational facilities for children with autism, which sometimes cost more to pay for education. Nearly half of parents accompanying a child with autism had a job as a housewife, and half of the respondents had an income above minimum wage. Information about autism is obtained by more than half of active parents by reading from books as a reliable source and followed by information from peer groups of parents who have autistic children, while only a tiny percentage get information from health workers through health education. The age of autistic children is known mainly at the age of 10-20 years, while the detection of autistic children is usually known after a more mature age.

Table 1.

Sociodemographics of Respondents' Parents and Childs

Characteristics Sociodemographics	Frekuensi	Frekuensi	Percentage (%)
Age Parents	31-40 years	12	54
	41-50 years	5	23
	>50 years	5	23
Level Education	Junior High School	1	5
	Senior High School	4	18
	Bachelor	17	77
Employment	Self-employed	4	14
	government employees	6	27
	Housewife	9	41
	private	3	14
Income	Above UMR (2.890.000)	11	50
	Under UMR (2.890.000)	11	50
Autism information	Read book	13	60
	Peer	5	23
	Health education	2	9
	Internet	2	4
Age child	5-10 years	6	27
	11-15 years	7	32
	16-20 years	6	27
	>20 years	3	14

Analysis Results

Table 2 shows that the indicators of social interaction disorder, communication disorders, and language development are the most widely understood knowledge by people with autistic children, with percentage values of 50% and 36.4%, respectively. Meanwhile, Table 3 illustrates that

family coping indicators of family support and acceptance of problems are often used by parents in caring for children with autism, with percentage values of 36.4% and 27.3%.

The description of the research variables in Table 4 shows that of the 22 parents, the level of parental resistance (64%) about autism is high, and there is a low level of knowledge, 23%. Family coping data showed that out of 22 parents, 14% had maladaptive coping mechanisms in caring for children with autism. Table 5 shows statistical tests with the Spearman test rank that parental knowledge about autism is positively associated with family coping adaptation in caring for children with autism ($p = 0.003$; $r = 0.599$). The study found that knowledge contributes to better family handling when caring for or caring for children with autism.

Table 2.

Table of Indicators of Knowledge Autism

Indicators	Knowledge level					
	High		Medium		Low	
	f	%	f	%	f	%
Social interaction disorder	11	50	2	9	2	9
Communication disorders and Language development	8	36.4	2	9	1	4.5
Obsessions and compulsive behavior patterns	3	13.6	1	4.5	0	0
Disorders and comorbid	2	9	0	0	0	0

Table 3.

Table of Indicators Family Coping

Indicators	Family coping			
	Adaptive		Maladaptive	
	f	%	f	%
Social support	2	9	1	4.4
Spiritual support	3	13.6	0	0
Family support	8	36.4	0	0
Acceptance of problems	6	27.3	2	4.5

Table 4.

Variable data on knowledge and family coping

Variable	Category	Frequency	Percentage (%)
Knowledge level	High	14	64
	Medium	5	23
	Low	3	13
Family coping	Adaptive	19	86
	Maladaptive	3	14

Table 5.

Results of analysis of the relationship between knowledge and family coping

Knowledge	Family Coping		r	P-value
	Adaptive	Maladaptive		
High	14 (73,7%)	0 (0%)	0,599	0,003
Medium	5 (21%)	1 (33,3%)		
Low	3 (5,3%)	2 (66,7%)		

Discussion

Important supportive interventions have been developed by healthcare providers to improve adaptability and coping mechanisms among parents with autistic children (Haytham et al., 2022), beginning with parents' understanding of autism disorders. This study shows that parental

knowledge contributes to the family's adaptable coping ability to provide care to children with autistic disorders ($p=0.003$; $r=0.599$).

Knowledge is obtained from information both orally and in writing from one's experience. The study results show that parents actively read books as an authentic source that can be trusted to gain knowledge related to autism in their children. Knowledge is a critical domain for forming one's actions in making decisions (Heil et al., 2022). Based on sociodemographic data, most of the parent respondents had undergraduate education. Education is essential to parents' total knowledge (Đurišić & Bunijevac, 2017). Our study illustrates that the most critical sociodemographic factor influencing total knowledge scores among parents of autistic children studied is education. This result agrees with previous studies (Yusuf et al., 2019). This can be explained by highly educated parents generating higher household income, media exposure, labour market participation, and health knowledge (Frank et al., 2019). Parent education is positively associated with healthy decisions, whereas parental education is more critically associated with long-term health outcomes (Rashighi & Harris, 2017). Education builds excellent knowledge and the ability to respond more quickly to new knowledge (Dong et al., 2020). The flow effect of educated parents is very important when dealing with stress, in this case, caring for children with autism (Deb et al., 2020).

Knowledge will also affect a person's coping mechanisms. However, it should be noted that changes in knowledge do not always lead to changes in behaviour and the coping mechanisms are chosen. Family knowledge about interacting and communicating with children with autism is essential to developing parental coping; previous research has shown that family communication is important for psychological health and well-being (Marra et al., 2020). Coping strategies are the main factor for protecting and maintaining psychological health and wellbeing in the face of adversity (Zsido et al., 2022). These findings indicate that individuals who experience positive family communication use more of a coping style approach, which in turn allows them to experience less psychological distress in dealing with adversity.

Family knowledge about obsessive and compulsive behaviour experienced by children with autism is important because the family will have a standard view of the behaviour shown by their child (Tyng et al., 2017). Characteristics of children with autism have been identified as possible sources of stress for families. However, despite the difficulties, some families still manage to achieve successful psychological adaptation (Maryam, 2017). Coping strategies refer to a group of behavioural or cognitive efforts aimed at reducing stress levels, and they are considered tools parents can use to adapt to the stress associated with raising a child with autism. Parents who adopted positive, problem-focused strategies reported less stress and better wellbeing than those who frequently used emotion-focused coping strategies, which were ineffective and did not resolve bad stressful situations (Le Vigouroux et al., 2023). This study shows that the indicators of social interaction disorders and communication and language development disorders are the most widely understood knowledge by parents who have children with autism, with a percentage value of 50% and 36.4% (Table 2).

A child with autism may have other comorbid symptoms in addition to the core symptoms of autism (e.g., social deficits, language disturbance, repetitive behaviour, etc.) (Al-Beltagi, 2021). Recognizing these medical conditions is essential because many medical conditions can stimulate or exacerbate the abnormal behaviour that occurs in autistic children. Comorbid conditions can be a marker of the underlying pathophysiology and require a more effective therapeutic approach (Tye et al., 2018). However, it is not always easy to identify comorbid conditions in children with autism

because of several factors, such as impaired communication, ambiguity of symptoms, deviation from the general population, or changes over time. Parents of individuals with autism often report high levels of stress and mental health problems related to challenges in caring for individuals with complex needs and navigating multiple service sectors throughout the life journey (Higgins et al., 2023). We know that high levels of distress are associated with the lower psychological wellbeing of parents and children and can indirectly affect parenting behaviour and child outcomes. Parents need to be helped to recognize coping resources in dealing with stress and burdens during the care of autistic children. Social and family support is essential in overcoming the problems parents face (Kalalo & Setiawati, 2020). This study illustrates that family coping indicators of family support and acceptance of problems are often used by parents in parenting children with autism with a percentage of 36.4% and 27.3% (Table 3).

Despite these limitations, this study provides insight into the factors of parental knowledge on family coping mechanisms while caring for children with autism. A comprehensive approach is needed in identifying coping mechanisms for families with children with autism because of the long stress span while caring for children with autism. Identification of factors that can help improve family coping mechanisms becomes a suggestion for further research to get a more comprehensive picture of solving the stress problem of parents with autistic children. In addition, this research involved parents with autistic children, who in society still consider it a disgrace for the family, so access to them is also limited.

Conclusion

Parents who have a high knowledge of autism disorders increase their ability to perform family coping mechanisms in caring for children with autism. Therefore, there is a need for education about autistic disorders for parents because good parental knowledge helps adapt to the stress experienced. They can provide care to children with autism because they have been able to adapt. The study reports that knowledgeable parents were found to be able to adopt adaptive coping strategies. More authentic and reliable sources of information about autistic children provide guidance and confidence for families in dealing with problems faced while caring for autistic children. Community health service supervisors can develop educational methods for families with autistic children to improve the ability of parents so that they can adapt to caring for children with autism.

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