

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

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Abstract

Background g: Cognitive, communication, social interaction, behavior patterns, and activity limitations in autistic children become a source of stress for parents. Parents' negative assessment of autistic children leads to maladaptive coping and results in inappropriate parenting behavior. **Objective:** This study focuses on evaluating parents' knowledge of autistic disorders and their relationship to coping in caring for children with autism. **Method:** *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 based on 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 Parisipans had high knowledge of autism and 14% of parents had maladaptive coping. The results of statistical tests found that the level of knowledge 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. 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 kuesioner *F-COPES McCubbin*. Kedua kuesioner tersebut merupakan alat yang sudah diuji reabilitasnya. Analisis statistik menggunakan *Rank Spearman test* dengan signifikansi 5%. **Hasil:** Parisipan 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, unable to observe and process information (Centers for Disease Control and Prevention, 2022a). Children with

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autism can be hampered in education and social relations. This disorder can be seen by the family and is recognized or diagnosed at the age of 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 in the world. 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 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 because the nature of autistic children has symptoms of severe anxiety, mood disorders, echolalia, difficulty adapting, and speechlessness (Yolanda et al., 2016).

Someone who is experiencing stress will tend to need a coping mechanism to reduce the stress (Dijkstra & Homan, 2016). Coping mechanisms are efforts made to overcome and reduce stress, including direct problem-solving efforts and ego-defense mechanisms used to protect oneself (Maryam, 2017). A family, when they find out that their favorite child has a disorder, the family 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 but makes the family learn about the child's condition and be strong in facing the reality about their child's condition, seek information in dealing with children with autism, 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 health care 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 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 which shows that knowledge about autism is still low even though the prevalence of good attitudes (Yusuf et al., 2019). The level of knowledge about autism in our setting is still lacking. Thus, because of the varying levels of knowledge around the world, it was important to assess this domain among parents in our setting. Because parents are directly involved in the care of 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 is able to seek literacy and adapt to care for their children well, therefore education by important 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 4 weeks from February to March 2020.

The population of this study is all parents who have autistic children who are studying at the River Kids inclusive school in Malang City, totaling 59 people, while the sample of this study is a portion of the population taken by consecutive sampling technique with the inclusion criteria of fathers or mothers who accompany them to school, willing to be a respondent, has one autistic child, and the age of an autistic child is more than 5 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 1 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 3 is about obsessions and compulsive behavior 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 has a level of reliability to measure 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. 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 showing 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 who 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 small percentage get information from health workers through health education. The age of autistic children is known mostly 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 pducation	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 childs	5-10 years	6	27
	11-15 years	7	32
	16-20 years	6	27
	>20 years	3	14

Analysis Results

The description of the research variables in Table 2 shows that of the 22 parents, the level of parental resistance is high (64%) about autism 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 3 shows statistical tests with Spearman test rank that the level of

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.

Variable data of 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 3.

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 developed by health care 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 results of the study show that parents are active in reading books as an authentic source that can be trusted to gain knowledge related to autism in their children. Knowledge is a very important domain for the formation of one's actions in making decisions (Heil et al., 2022). Based on socio-demographic data, most of the parent respondents had undergraduate education. Education turned out to have an important effect on parents' total knowledge (Đurišić & Bunijevac, 2017). Our study illustrates that the most important sociodemographic factor influencing total knowledge scores among parents of autistic children studied is education. This result is in agreement with other previous studies (Yusuf et al., 2019). This can be explained by the fact that highly educated parents can generate greater household income, more media exposure, labor market participation, and higher 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 greater 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 behavior, and the coping mechanisms chosen. Family knowledge about how to interact and communication with children with autism is an important part of developing parental coping, previous research has shown that family communication is an important factor for psychological health and well-being (Marra et al., 2020).

Coping strategies serve as the main factor for protecting and maintaining psychological health and well-being 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 behavior experienced by children with autism is important because the family will have a normal view of the behavior shown by their child (Tyng et al., 2017). Characteristics of children with autism have been identified as possible sources of stress for families. However, some families, despite the difficulties, still manage to achieve successful psychological adaptation (Maryam, 2017). Coping strategies refer to a group of behavioral 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 well-being than those who frequently used emotion-focused coping strategies, which were ineffective and did not resolve bad stressful situations (Le Vigouroux et al., 2023).

A child with autism may have other comorbid symptoms in addition to the core symptoms of autism (eg, social deficits, language disturbance, repetitive behavior, etc.) (Al-Beltagi, 2021). Recognizing these medical conditions is important because many medical conditions can stimulate or exacerbate the abnormal behavior 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 with navigating multiple service sectors throughout the life journey (Higgins et al., 2023). We know that high levels of distress are associated with lower psychological well-being of parents and children and can indirectly affect parenting behavior 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 an important aspect in overcoming the problems faced by parents (Kalalo & Setiawati, 2020).

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, so as to get a more comprehensive picture in 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 the ability to perform family coping mechanisms in caring for children with autism. Therefore, there is a need for education about autistic disorders to 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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