

Coping strategies of mothers with children with autism spectrum disorders living in Indonesia during COVID-19

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Abstract

This study aimed to explore the experience of learning coping strategies from home carried out by mothers who have autistic children during the COVID-19 pandemic in Indonesia. Six mothers who have autistic children of school age were taken as informants, and they were interviewed online. The collected data was then analyzed using thematic analysis. The results of the study show six themes related to the experience of learning coping strategies from home carried out by mothers who have autism spectrum disorders children, during the COVID-19 pandemic: knowing information on how to educate children is half a win from the ability to adapt. Also, to succeed, a person must: have many issues but maintain self-control; recognize that parents have an obligation to educate their children; know when a burden is too great to be eased gradually; and the greatest person to rely on is God, who is sufficient as an assistance.

Keywords: Autism spectrum disorders; coping strategies; COVID-19; learning from home; mothers

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1. INTRODUCTION

Since late 2019, the severe acute respiratory illness caused by the coronavirus (COVID-19) has swept the world. The coronavirus disease has infected various countries which made the situation and attention a health emergency until the World Health Organization declared it a pandemic. The education sector is one of those affected by the COVID-19 pandemic in addition to other sectors, both formal and informal (Daulay, 2021). One of the impacts on the education sector is the complete discontinuation of the implementation of learning in schools and the replacement of the implementation of learning from home, including the implementation of learning for children with special needs, with disorders such as autism spectrum disorders (ASD) (Averett, 2021).

Autism spectrum disorder (ASD) is a neurobiological developmental disorder that is very complex or severe in life and is characterized by difficulties in interests, activities, communication, and social interaction, with restricted and repetitive behavior patterns (Daulay, 2021; Loyola de Souza Guevara et al., 2024), and almost all aspects of its development experienced difficulties (Karst & Hecke, 2012). ASD children also have difficulty adjusting to a new environment/situation, such as during the outbreak of COVID-19 (Espinosa et al., 2020; Martin et al., 2024; Egan et al., 2024). In addition, they usually have various co-morbidities, such as excessive anxiety, learning disabilities, epilepsy, Down's syndrome, frequent altered immune systems, and more (Peters-Scheffer et al., 2012; Simonoff et al., 2008). By definition, symptoms appear early in development, affecting daily functioning (American Psychiatric Association, 2013). The number of cases of autism has increased from 1 per 150 population in 2000 to 1 per 59 in 2014 (CDC 2018).

Parenting for ASD children is difficult, and greater pressure even creates stress and anxiety (Bitsika & Sharpley, 2017). The stress experienced by mothers in caring for children with ASD is higher than that of mothers of children without disabilities (Giovagnoli et al., 2015; Rao & Beidel, 2009), becoming the emotional and coping basis that increases parental capacity. In addition, before the COVID-19 outbreak occurred, the implementation of ASD education was usually carried out in schools, dismissed due to the COVID-19 situation by replacing learning from home. According to Narzisi (2020), the implementation of learning from home presents a very difficult challenge, especially for ASD compared to normal children.

The occurrence of a pandemic has forced parents to adapt to various situations, such as changes in their child's behavior. The burden on parents is getting heavier because apart from teaching their children to study at home, they are also still doing domestic tasks such as washing clothes, washing dishes, cooking, preparing food, sweeping the house, and providing for children's needs. In addition, they have to think about making ends meet due to the reduction in family finances due to the pandemic (Anderson et al., 2024). Thus, the pandemic situation makes the mother's condition even more alarming and creates a heavy burden on parenting.

The existence of a pandemic and schools implementing learning from home makes parents confused by the changes that occur, both to themselves, their children, their families, and the existing situation. Regarding the behavior of ASD children, they develop maladaptive attitudes, such as excessively active behavior, disobedience to orders, difficulty managing and often hyperactivity, disobeying instructions, difficulty controlling, and instinctive. Mothers find it difficult to educate their children, especially because of the lack of insight into how to teach children at home, which is a source of stress. The lack of insight in teaching children from the mother's home also causes uncertain thoughts and feelings such as anxiety, irritation, and anger when communicating with children at home. Overcoming the difficulties of children with ASD when learning from home with certain coping strategies is one of the important and main mechanisms for parents to adapt to stress and anxiety when parenting a child with ASD (Benson, 2014).

1.1. Literature review

1.1.1. Coping strategies for parents who have autistic children

Coping is defined as an individual process of responding to stress. Meanwhile, for parents with ASD children, Hastings et al., (2005) identified several coping strategies, such as being active-avoiding stress; focusing on addressing problems by planning and seeking appropriate social support; engaging in positive coping; and using religion or spirituality. Hastings et al. (2005) also found that problem behavior among children with ASD was associated with maternal use of maladaptive coping strategies, which in turn resulted in higher maternal stress.

Existing research to date has emphasized the use of coping strategies used by mothers of ASD children. These strategies have been identified as important mechanisms for managing physical exhaustion and stress for parents and in improving well-being, also finding that active avoidance, use of religion, and denial-based coping strategies were reported to be maladaptive for mothers of children with ASD, where this strategy was found to hurt maternal well-being and lead to higher levels of stress, anxiety, and depression (Seymour et al., 2013).

Ansari (2002) argues that mothers of children with special needs feel responsible for their children's behavior because they are more involved in their upbringing. When the child does not succeed in responding or there is a stagnation of ability, the mother blames herself for failing to raise the child. Minhas et al., (2015) reported that mothers were blamed by local community members for not atonement for their sins, and therefore they were given disabled children. Papageorgiou & Kalyva (2010) as well as Yu et al., (2018) show that parents who have limited support and resources must try to be stronger, especially in families with additional care, and become a source of even higher stressors.

1.1.2. Learning from home for autistic children in Indonesia

In Indonesia, it has been confirmed in the 1945 Constitution Article 31 paragraph 1 which explains that every citizen has the right to education, including children with special needs. (Sheehy & Budiyanto, 2014; Daulay, 2021). Educational services for children with growth and development disorders are provided through, (1) special schools, where education services are only for children with special needs, by separating them from normal children, and (2) an inclusive education system, which allows children with learning disabilities together with their healthy peers, in regular schools (Ghufron & Nasir, 2019). Meanwhile, in 2007, the Indonesian government legalized home learning based on the Law of the Republic of Indonesia Number 20 of 2003 concerning the National Education System. In addition, home education is an educational model that places the family as the main educator (Daulay, 2021).

Before the pandemic, the education of ASD children was usually carried out in schools, supported by various supporting programs, a curriculum that was on the needs, completeness of facilities and infrastructure, and competent human resources such as teachers, therapists, and psychologists (Plak et al., 2023), family involvement and appropriate evaluation (Roberts & Webster, 2022; Yarımkaaya & Esentürk, 2020). However, when COVID-19 became an epidemic throughout the world, including in Indonesia, education services for children with special needs, including ASD in schools, were stopped and replaced with learning from home (Daulay, 2021).

The implementation of learning from home is an effort to renew the education of countries around the world with an emphasis on where the implementation of educational services can be at home or other places (Cahapay, 2022), and has been demonstrated primarily in the United States, United Kingdom, and Australia (Kidd & Kaczmarek, 2010) and existed before the pandemic. Learning from home is also another learning service preference for ASD children, during the pandemic (Cahapay,

2022; Espinosa et al., 2020; Majoko & Dudu, 2022). Several studies related to learning from home have been carried out, especially on children with disabilities (such as Simmons 2016, Mendoza et al., 2019). Research on the role of parents in learning from home for ASD children was conducted (such as Reilly et al., 2002; Kidd and Kaczmarek 2010; Parsons and Lewis 2010; Hurlbutt 2011; Jolly et al., 2013). However, unprecedented pandemics including COVID-19, have not been widely investigated (Rose et al., 2022).

However, as stated by Luthra & Perry (2011), learning from home also has limitations such as minimal parental insight regarding ASD children making the learning process at home not optimal. Meanwhile, according to Cahapay (2022), inappropriate behavior of ASD children is getting out of control, such as children who are excessively active, irritable, dependent on people around and tantrums (Gregor et al., 2018); the implementation of learning from home is not going well for children with disabilities due to the lack of skills assistance for physical needs (Narzisi, 2020), getting tension in the family of ASD child nurses (Espinosa et al., 2020; Rose et al., 2020); there have been various changes due to the pandemic that have made parents have problems adjusting (Majoko & Dudu, 2022).

1.2. Purpose of study

Several studies on coping strategies of parents who have ASD children have been carried out, such as research by Furrukh and Anjum (2019), Seymour et al., (2013), Miranda et al., (2019), Pozo & Sarriá, (2014), Al-Kandari et al., (2017), Lindsey & Barry, (2018). Most existing research focuses on parental coping strategies in ASD children in general, while research that focuses more on learning from home during the pandemic is minimal. Therefore, this study aims to explore the experience of parental coping strategies in educating ASD children from home and during the COVID-19 pandemic in Indonesia. This research is expected to provide insight into the challenges and opportunities of coping strategies for other parents when educating their ASD children at home amid a global health emergency.

2. METHOD AND MATERIALS

2.1. Research design

A qualitative research design was used in this study. Creswell (1994) defines qualitative research as a mechanism for investigating social problems or human problems, based on constructing a complex and integralistic picture, formed in words, reporting detailed views of informants, and carried out in a natural setting. The research design used is very appropriate to achieve the goal of describing the experience of coping strategies for learning from home carried out by parents who have ASD children.

2.2. Participants

Participants in this study were six Indonesian mothers. Participants were selected through a combination of purposive sampling and convenient sampling techniques. The main criteria considered for selection were that (1) the mother must have at least one child diagnosed with an autism spectrum disorder (ASD). (2) Be the biological parent of a child with ASD; (3) Caring for their ASD child at home during the pandemic (4) their children are registered for at least one year and have been through the learning process as students in special schools.

This research was conducted during September 2020, when the COVID-19 virus was spreading. This research begins with the preparation to collect data about the participants. Ten parents were initially contacted, however, only six responded positively to participate. The demographic qualities of the participants are described in Table 1.

Table 1
Demographic quality of participants

Sociodemographic Characteristics	Participants					
	A	B	C	D	E	F
Age	42	38	40	38	37	39
Level of education	senior High School	S1	S2	S1	senior High School	senior High School
Marital status	Marry	Marry	Marry	Marry	Marry	Marry
Profession	self-employed	civil servant	Lecturer	Teacher	Housewife	Housewife
Income per month	IDR 1.5 million	IDR 3.5 million	IDR 5 million	IDR 3.5 million	IDR 1.2 million	IDR 1.1 million
Number of children	4	3	2	2	3	2
Family Members (Other than ASD children)	Father, Mother, 3 siblings	Father, Mother, 2 siblings, Grandpa and Grandma	Father, Mother, 1 sibling	Father, Mother, 1 sibling	Father, Mother, 2 siblings	Father, Mother, 1 sibling, Grandpa, and Grandma
Family Status	Main family	Big family	Main family	Main family	Main family	Big family
ASD child age	7	8	14	6	10	9
ASD child gender	Girl	Boy	Girl	Boy	Girl	Boy

The second stage is the implementation stage. At this stage the six participants were contacted via WhatsApp, made introductions, built relationships, and explained the research objectives. After the entire approval and clarification process was carried out, the next stage was data collection.

2.3. Data collection

In-depth online interviews were used to reveal the experiences of mothers with ASD children about coping strategies for learning from home. An online interview guide has been prepared which contains how to experience coping strategies for implementing learning from home during the COVID-19 outbreak. Interviews are conducted once for 60-90 minutes and will be conducted again if anyone wants to verify data. As with personal interviews, online interviews are conducted by requiring participants to reflect on their thoughts and feelings about a particular subject (Salmons, 2014). Online interviews with permission from participants to use assistive devices in the form of smartphones to make calls for the interview process with the help of WhatsApp, with audio recording facilities.

2.4. Data analysis

Data obtained from interviews became the subject of thematic analysis. Thematic analysis is an analysis that is carried out systematically through the process of coding, checking meaning, and providing an overview of social reality through the creation of themes (Berg and Latin 2008). In this study, researchers review existing codes and translate them into concepts. Similar concepts are then grouped into themes, and the results are arranged to answer the research objectives. The theme is the main product of this data analysis.

3. RESULTS

The findings of this study identify six themes, which are related to the experience of learning coping strategies from home carried out of homes during the COVID-19 outbreak in Indonesia carried out by mothers who have ASD children, which will be explained as follows.

3.1. Theme 1: Knowing information on how to educate children is half the win

Based on interviews with the six participants resulted in coping strategies for learning from home for parents of children with ASD. Parents' efforts to reduce obstacles in carrying out learning from home include seeking support through WhatsApp community groups for parents of students with autism. Community groups have a very large role psychologically in supporting and disseminating information about parenting practices during the pandemic.

I joined a WhatsApp group and got various information, and positive support from parents who have other autistic children who can help me and my family in facing the existing conditions positively (C).

Meanwhile, searching for knowledge and information that is suitable for children's conditions through print and online media was carried out by two of the six participants.

Learning from home is the first time I have experienced this. So frankly I'm confused about how to teach children at home. Even though children are used to the situation at school. So, I actively searched for information through Google regarding how to educate ASD children during an emergency such as a pandemic in addition to discussing with teachers online via WhatsApp (B).

3.2. Theme 2: From adaptability to success

The support mothers receive from teachers, or community groups can help them in teaching their children at home. Four out of six participants tried to deal with the problem, and efforts to overcome the problem gradually. For information from teachers, parents try to carry out as well as possible because teachers have a lot of understanding of the characters, and habits their autistic children did when they were still in school and before the pandemic occurred.

Learning information that comes from my child's teacher will usually be done as well as possible, such as doing all the habits that exist at school, so I will try to do it at home. Because the teachers have educated my child before the pandemic, they know about my child so I believe it will be good for my child even though sometimes one or two habitual activities are not appropriate (E).

Meanwhile, two out of six participants selected and analyzed any information from the community considering that not all information about learning in children with autism was appropriate for their children. Therefore, parents usually make adjustments to the circumstances and conditions of their children. Including differences in children's behavior and daily routines.

There have been many changes in all normal human behavior, especially in my child during this pandemic. Therefore, I usually select any learning information from the community first. Is it suitable or not for my child? Because, even though they are both autistic, their handling must usually be adjusted to the child himself. (D).

However, this was not the case with one of the participants who has been caring for their autistic child for eight years. Participants can adapt well when educating their children at home during the COVID-19 outbreak. This condition is because these participants are used to teaching their children academic skills and independence directly. After being diagnosed with ASD, these participants intensively teach children at home and also send them to special schools to develop their children's potential.

3.3. Theme 3: When the load is too heavy it is lightened by letting go slowly

The burden of caring for mothers is preparing food, and clothes, cleaning the house, and preparing all the children's needs as the main household tasks apart from a reduction in income. Mother's efforts in reducing and dealing with stressful situations based on the results of interviews with the four participants said that they usually surrendered and gave up or did nothing about the source of the stress. Participants perform behavioral disengagement or do "abandonment" when they feel that whatever they do will not produce results which is often called "Helplessness".

The implementation of learning from home that I do for my children cannot run optimally during this pandemic, because everything is done by me. Meanwhile, my son [ASD] is too lazy to study, difficult to manage, and prefers to watch TV at home. Moreover, I have to take care of household chores and still have to work to make ends meet. Yes, sometimes it makes me feel bored, stressed, and tired, that's why I'm often tired and I just let it go "fluffy" (A).

3.4. Theme 4: Lots of problems but keep yourself in control

Confused, feeling that the burden is getting heavier in carrying out learning from home was reported by three participants with changing situations and circumstances. When the child learns from home, the mother starts from the beginning learning to understand the child. Children's behavior habits have become changed, which is children's behavior habits have changed, such as neglecting orders, and maladaptive, overactive, and instinctive behavior. Not to mention there is a decrease in income from her husband. At such times, the participants are usually silent, calm themselves, have good prejudice with the existing conditions, and be careful in acting and teaching children.

Children prefer to watch TV and play rather than study. When forced, the child even rages. At such times I prefer to be quiet, restrain myself, not be nervous, and remain grateful for what I have (C).

Three participants came from middle-class families. The other three participants came from low-income incomes with a salary of less than 1.5 million Indonesian rupiah (equivalent to 107 USD). The last three participants are housewives who only rely on their husbands to provide for their daily lives, which makes the mother try to help meet all household needs by taking care of all household chores and children. However, the husband's income has decreased alarmingly during the COVID-19 outbreak. During a pandemic with less than usual income, even half the usual, they find it difficult to meet family needs for a whole month. With the existence of a pandemic, sources of stress become more and more making the parental burden. With the existing conditions, the mother tries to solve the problem by controlling herself, trying to be patient, restraining herself, regulating feelings, and being thorough and unhurried in taking action.

3.5. Theme 5: Parents have a responsibility to educate their children

The two participants revealed that whatever happened regarding the condition of their children, the conditions of the pandemic situation, and the government's policies that enforced learning from home were accepted with grace. Participants will continue to do their best to care for and educate children as well as possible. Participants are aware of their responsibility in the problems they face and try to accept and hope that all conditions will be better.

Even though I feel heavy during a pandemic like now. However, because that's the child's need, we as parents must try to fulfill it (D).

Four participants revealed that the implementation of learning from home caused behavioral changes in their children, such as children being separated from supervision because the mother also has to take care of her brother or sister and household chores, not yet because of the mother's limited insight regarding the implementation of learning at home also became obstacles even become irritable and stressed. However, participants stated that their children are their responsibility.

The pandemic has changed the behavior of my children at home, irritable, crying, and difficult to control. Even though I still have to take care of my sister, I haven't cooked washed, and prepared all other necessities for the family, making me easily irritated and stressed. But I still have to fulfill them and my responsibilities because they are my children... my family (F).

3.6. Theme 6: God is sufficient as a Helper and the best place to lean on

The six participants looked for positive things from what they were doing at the moment. As with the pandemic, you can know and understand your child more deeply and closely. With the pandemic situation and conditions, children are involved with other families in religious life. The six participants tried to divert the problems they faced by doing activities related to religion, including diligently worshipping, and asking for God's help. The six participants stated that praying a lot and being patient is an effort to reduce discomfort and even stress when interacting or providing learning services from home to children, making mothers more flexible and psychologically motivated in facing obstacles during the pandemic. Uncertain conditions like now, who wants to be angry with? Who do you want to blame? Yes, I surrender to Allah, pray and pray, and spend time alone in my room hoping that it will all end soon (D).

I am often irritated because children prefer to watch TV than study, children become difficult to manage and act a lot. At such times I "let go" of feelings and immediately restrain myself (E).

Despite the report that there were many obstacles in learning from home services during the COVID-19 outbreak, all participants believed that they would be able to endure adversity, and remained optimistic that they could get through it well.

4. DISCUSSION

Coping strategies in overcoming difficulties in carrying out learning from home in children with ASD is a process of a mother adapting to stress and managing anxiety when carrying out learning from home in children with ASD. This study found that the mother's coping strategy is to continue to carry out the learning process from home as best as she can even though she does not have teaching experience by continuing to carry out instructions from the teacher and seeking information on how to teach through print and social media and adapted to the condition of her child.

Children with developmental disorders such as ASD children have different behaviors, emotions, cognitions, and social interactions from healthy children due to developmental abnormalities in the nerves that also affect brain function (American Psychiatric Association, 2013), seen with children showing inappropriate behavior such as irritability, tantrums, and hyperactivity. Eshraghi et al., (2020) explained that outdoor activities are decreasing due to the lockdown, which according to Espinosa et al., (2020) makes learning from home not optimal and makes children maladaptive. The results of this study indicate that parental knowledge about children and how to educate them during the pandemic is the main capital for the success of the learning process from home. Therefore, mothers continue to seek information and knowledge in teaching (King et al., 2012) to avoid the emergence of inappropriate behavior in children.

Learning from home during the pandemic makes children learn new habits. Previously, children were more accustomed to learning at school with their teachers, while learning from home had to be with their mothers, which was not the case before. Several studies have found that, compared to fathers, mothers experience a heavier parenting burden (Jones et al., 2013), feel heavy and uncomfortable physically and spiritually (Cetinbakis et al., 2020), experiencing tension, easily despair, lethargy and anxiety (Eyuboglu & Eyuboglu, 2020; Leung et al., 2023), stress in parenting (Gallagher & Whiteley, 2012). The results of this study are also to the results of research by Corcoran et al., (2015)

which shows that the skills of parents to adapt to various situations, especially mothers, are the next coping strategy and the key to children's success in education.

Relation theory explains that what parents do will affect their children's behavior. Thus, there is a two-way and transactional relationship between parents and children (Neece et al., 2012), as the attitudes and behavior of children are a reflection of the attitudes and behavior of their mothers. The burden of parenting, difficulties for mothers, and educational services at home for their children is also heavier when the children's disorders and limitations are also severe. A mother becomes more likely to suffer from stress-related behavior problems with children (Depape & Lindsay, 2015). The results of this study show that mothers also use behavioral disengagement coping strategies or do "abandonment" when they feel that whatever they do will not produce results. The results of this study are the results of research by Benson (2010), where the coping strategies of mothers who have children with ASD include release with release directed at withdrawing from stressors through rejection and giving up trying to overcome them.

Mother's self-control is an important part of parenting (Li et al., 2019). The results of this study also use self-control as a coping mechanism in dealing with various burdens, when they feel weak, tired, lethargic, bored, frustrated, and worried about the existing situation, but they have to keep doing and completing these responsibilities besides teaching their children from home. However, Ogston et al., (2011) emphasize the magnitude of the parenting responsibility for mothers who have ASD children. After all, children with all their conditions are the responsibility of parents, especially mothers. And is a cognitive reframing coping strategy, consisting of a mother's efforts to "adjust" to their autistic child positively through acceptance, and cognitive restructuring (Benson, 2010) which is also a lifelong coping strategy needed to treat ASD children (Shepherd et al., 2018).

This study also shows how to deal with sources of stress by mothers through religious coping (Das et al., 2017), praying (Huang & Zhou, 2016), and reading the Koran to reduce anxiety (Habib et al., 2017). especially when experiencing difficulties in carrying out learning from home. Religion is a source of positive energy for spirituality, and psychological functioning (Koenig et al., 1997), through the support of religion and spirituality, personal well-being is improved even under great stress (McFadden & Levin 1996). Religion also has an important role in guiding, directing, and enlightening someone when faced with problems (Zinnbauer et al., 2015), increasing self-restraint (Subandi, 2011; Furrukh & Anjum, 2020), and creating happiness (Krok, 2014); religion and spirituality as coping provide strength in facing difficult times (Kwon, 2015), even still find happiness because of their connection with their beliefs and values (Stefanek et al., 2005).

5. CONCLUSION

In essence, this study explored the experience of Indonesian mothers' coping strategies in carrying out learning from home for their ASD in Indonesia, however, there are some limitations in this study. The mother's coping strategy is to continue to carry out the learning process from home to the best of her ability even though she has no teaching experience by continuing to carry out instructions from the teacher and seeking information on how to teach through print and social media and adapted to the condition of her child. Mothers carry out behavioral disengagement or "abandonment" when they feel that whatever they do will not produce results which is often called "helplessness". At certain times, mothers are usually silent, calm themselves, have good prejudice with the existing conditions are careful in acting and teaching children, and continue to educate their children as well as possible considering that their children are their responsibility. In addition, mothers also carry out activities related to religion, including diligently worshipping, praying, being patient, and asking God for the best help.

Despite its contribution to providing new information on maternal coping in implementing learning from home for ASD children in Indonesia, this study has several limitations. First, the informant regarding coping with learning from home only involved the mother of an ASD child and did not involve

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the father figure in this study, which may be due to the lack of comprehensive data obtained. Second, to reveal the experiences of the participants, this study was limited to using a qualitative approach, therefore this study cannot be generalized to other learning-from-home mothers who educate children who have different needs; therefore, it is recommended for further research to use varied methods such as using the qualitative and quantitative combinations also involve varied and more participants.

Conflict of Interest: The authors declare no conflict of interest.

Ethical Approval: The study adheres to the ethical guidelines for conducting research.

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