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To cite this article:

Karnas, M. (2023). What coping strategies do parents of children with autism use to cope with stress? International Journal on Social and Education Sciences (IJonSES), 5(3), 722-735. https://doi.org/10.46328/ijonses.618

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2023, Vol. 5, No. 3, 722-735

https://doi.org/10.46328/ijonses.618

What Coping Strategies do Parents of Children with Autism use to Cope with Stress?

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Article Info

Article History

Received:

25 January 2023

Accepted:

04 June 2023

Keywords

Parents of children with Autism Spectrum Disorders Stress levels of parents Coping strategies

Abstract

Parents of children with Autism Spectrum Disorder (ASD) have higher levels of stress compared to parents of children with other disabilities and parents of typically developing children. According to the Centers for Disease Control and Prevention, the prevalence of ASD in U.S. children increased from 1 in 150 in 2000 to 1 in 54 in 2016, which means that for every 1 out of 54 children, there might be at least one parent who is facing higher levels of stress. Parents use some coping strategies to manage their stress. Studies that have investigated the association between stress levels of parents and their coping strategies have often grouped coping strategies together and have not examined them individually. This study surveyed 144 parents to investigate the association between stress levels of parents and the individual coping strategies they use. The Parental Stress Index-Short Form-fourth edition (PSI-4-SF) and the adapted Brief COPE inventory were used to gather the data. Descriptive statistics and the chi-square test of independence were employed for the analysis of the data. Results of the study indicated that there was a statistically significant association between parental stress and six coping strategies including behavioral disengagement, self-blame, humor, venting, instrumental support, and denial.

Introduction

All parents experience some level of parenting stress, as having a child brings additional responsibilities (Craig et al., 2016). Parenting stress is defined as an unpleasant psychological reaction to the demands of being a parent, especially when parenting demands exceed the actual and expected resources available to parents (Liles et al., 2012). Having a child with a disability can result in higher levels of parenting stress for many parents because of the increased demands associated with raising a child with a disability (Lazarus & Folkman, 1984; Osborne et al., 2008). Especially, parents of children with Autism Spectrum Disorder (ASD) have reported higher levels of stress than parents of children with other disabilities and parents of typically developing children (Baker, & McIntyre, 2003; Lai et al., 2015; Weiss et al., 2013). The research indicated that higher levels of parental stress is associated with (a) challenging characteristics of ASD (Ekas & Whitman, 2011; Silva & Schalock, 2012); (b) parent-related factors such as having a negative approach to disability (e.g., grief, anger, and disappointment) (Costa et al., 2017); (c) inadequacy in financial resources and appropriate services (Montes & Halterman, 2008); and lack of knowledge and training pertaining to the disability (Bendixen et al., 2011; Dababnah & Parish, 2016).

According to the Centers for Disease Control and Prevention (CDC), the prevalence of ASD in U.S. children increased from one in 150 in 2000 to one in 54 in 2016 (CDC, 2017). Taking into consideration the recent prevalence rate of ASD in the United States, one in every 54 parents is likely to experience higher levels of stress as a result of raising a child with ASD. Abidin (2012) categorized parent stress in three groups: parents with normal levels of stress, parents with high levels of stress, and parents with clinically significant levels of stress. Parents with higher levels of stress were considered as parents possibly needing professional consultation, and parents with clinically significant levels of stress were considered as parents definitely in need of professional consultation (Abidin, 2012). Having higher levels of stress may not only adversely affect parents' health, but also may limit their ability to provide effective interventions for their children with ASD (Osborne et al., 2008).

Parents of children with ASD have been using different types of coping strategies to deal with their stress (Hall & Graff, 2011). Coping strategies are defined as groups of cognitive or behavioral efforts used by individuals to decrease or minimize their stress level (Lazarus and Folkman, 1984). Carver (1997) defined 14 coping strategies in Brief COPE inventory. The list of these coping strategies are listed in Figure 1.

Brief COPE (Coping strategies)

- 1. Active Coping: Taking action to make situation better.
- **2. Use of emotional support:** Getting emotional support from others.
- 3. Use of Instrumental support: Getting help or advice from other people.
- **4. Positive Reframing:** Looking for something good in the situation.
- **5. Planning:** Coming up with a strategy about what to do.
- **6. Acceptance:** Learning to live with the situation.
- **7. Religion:** Finding comfort in spiritual belief.
- **8. Self-distraction:** Turning to other activities to think less about the stressors.
- **9. Denial:** Refusing to believe the situation.
- 10. Substance use: Using alcohol or drug
- 11. Behavioral Disengagement: Giving up trying to deal with.
- **12. Venting of emotions:** Expressing negative feelings.
- 13. Humor: Making fun of the situation.
- 14. Self-Blame: Criticizing himself/herself.

Figure 1. Coping Strategies in Brief COPE Inventory. Developed by author based on data in Carver (1997).

Lazarus and Folkman (1984) categorized coping strategies into two groups as problem-focused and emotion-focused coping strategies. This categorization is the most famous one and often used by studies on coping strategies (Benson, 2014; Garcia et al., 2018; Lin, 2015). Problem-focused coping strategies aimed to solve problems or change the source of the problems. Emotion-focused coping strategies aimed to reduce or manage feelings of distress (Lazarus & Folkman, 1984). Research regarding problem-focused and emotion-focused coping strategies consistently indicated that problem-focused coping strategies are mostly associated with lower levels of stress when compared to emotion-focused coping strategies (Benson, 2010; Obeid & Daou, 2015).

Some researchers suggested that categorizing the coping strategies into two groups might oversimplify the way parents respond to stress; therefore, more categorization is needed (Endler & Parker, 1990; Benson, 2014). Endler and Parker (1990) suggested including another category, avoidant strategies that are aimed to avoid stressful situations. Some other researchers categorized the coping strategies into four groups—engagement, disengagement, distraction, and cognitive reframing (Benson, 2010, 2014; Obeid & Daou, 2015). Some of these studies found that distraction and disengagement coping strategies were predictors of poorer well-being among mothers of children with ASD (Benson, 2010, 2014; Hastings et al., 2005; Obeid & Daou, 2015). Several other studies categorized coping strategies into four other groups—problem-focused, active avoidance, positive coping, and religious/denial coping strategies (Hastings et al., 2005; Lai et al., 2015). Studies that investigated these groups suggested that active-avoidant and religious/denial coping strategies were associated with higher levels of stress and decreased well-being among parents of children with ASD (Benson, 2010; Dabrowska & Pisula, 2010; Hastings et al., 2005).

The review of the literature employed Brief COPE inventory indicated that numerous studies indistinctly classified religion, positive reframing, humor, and acceptance as problem-focused, emotion focused, or avoidant coping strategy (Schnider, Elhai, & Gray, 2007). For example, Benson (2010) included humor in the distraction coping strategy group, which was stated not to be an effective coping strategy group. On the other hand, Hastings et al. (2005) included humor in the positive coping strategy group that was stated to be an effective coping strategy group. In order to clarify the ambiguity in literature, the purpose of this study was to investigate the association between parental stress and 13 coping strategy, except substance use, from the Brief COPE inventory used by parents of children with ASD. Substance use was removed from the present study because of ethical concerns regarding asking participants whether they use any substance to cope with their stress. In order to achieve the purpose of the study, the following research question was asked for each of these 13 coping strategies in Brief Cope inventory: "Is there an association between coping strategies used by parents of children with ASD and their stress levels?"

Methodology

Participants

Parents of children with a confirmed diagnosis of ASD were invited to participate in this study. Approximately 2,900 parents of children with ASD were invited through a Special School District from Midwestern city and two non-profit organizations. Names of the city, Special School District and organizations are not stated for the purpose of confidentiality. The study was conducted using an Internet-based survey questionnaire to collect data. Both fathers and mothers were eligible to participate because research has indicated having a child with ASD impacts the stress levels of both fathers and mothers (Rivard et al., 2014). Wright et al. (2015) addressed that the demands and requirements of caring for a child with ASD may be the same for older children with ASD. Therefore, parents who had children with ASD from birth to 21 years old were invited to participate in the study. A total of 172 parents from all invitees agreed to participate in the study. Twenty-eight participants did not replay to all the questions. 144 participants answered all the questions except three participants who did not report their annual family income. Of those all participants, 119 were mothers and 25 were fathers. The average age of

participants was 45. Forty participants were single, while 104 participants were married (see Table 1). Participants were categorized into three categories regarding their annual family income. Only 19 participants had less than \$49,999 annual family income, while 51 participants had an annual family income between \$50,000 and \$99,999, and 71 parents had more than \$100,000 annual family income (see Table 1).

Table 1. Demographic Characteristics of the Study Sample (N=144)

Demographic/Response	Sample <i>n</i>	Sample %	
Gender			
Male	25	17.4	
Female	119	82.6	
Marital status			
Married	104	72.2	
Single	40	27.8	
Annual Family Income			
Less than or up to \$49,000	19	13.5	
\$50,000-\$99,999	51	36.2	
\$100,00 or more	71	50.3	

Data Collection Tools

Two surveys, including the adapted Brief COPE inventory and PSI-4-SF, were combined into one online survey to collect data. Demographic data pertaining to gender, Marital status and, annual family income were collected in the survey. Prior to the beginning of the survey, participants were informed about the study's purpose and asked to provide informed consent.

Brief COPE

The Brief COPE is a 28-item self-report questionnaire developed by Carver (1997) to assess the types of coping strategies that parents of children with ASD utilize. This tool includes 14 coping strategies and each coping strategy has two items. Mean scores of the two survey items are used to score each coping strategy. One of the key features of the Brief COPE survey is that coping strategies are individual and researchers who want to use Brief COPE can select the coping strategies based on their research interests (Carver, 1997). This study excluded the "substance use" coping strategy because of ethical concerns from the Brief COPE survey; hence, for this study, an adapted Brief COPE survey with 13 coping strategies was used (26 items). Each question in the Brief COPE is rated on a 4-point Likert-type scale ranging from 1 (*I have not been doing this at all*) to 4 (*I have been doing this a lot*). Internal reliability for the 14 strategies ranges from 0.53 to 0.93 (Benson, 2010; Carver, 1997).

Parenting Stress Index-4th edition-Short Form (PSI-4-SF)

The PSI-4-SF is a 36-item screening tool developed by Abidin (2012). The items in the tool are scored using a 5-

point Likert-type scale ranging from 1 (*strongly agree*) to 5 (*strongly disagree*). The PSI-4-SF yields scores on total stress and includes three subscales that measure the following: (a) parental distress, (b) parent-child dysfunctional interaction, and (c) difficult child. The PSI-4-SF survey results allow researchers to categorize parents into three groups based on their total stress scores. Total scores for participants' stress levels are obtained by adding all items in the row. The raw scores between 54 and 109 is considered normal, between 110 and 113 is high, and 114 and above are considered clinically significant levels of stress (Abidin, 2012). The reliability coefficients of the PSI-4-SF are reported as 0.84 for total stress (Abidin, 2012). This study only used the total stress scores.

Analysis of Data

This study used the cross-sectional survey method to collect the data. The data was analyzed using the descriptive statistics such as frequencies and percentages to describe the characteristics of collected data, and chi-square test of independence which is a useful method to determine whether there is a significant association between categorical variables (Terrel, 2012). SPSS software was used for the data analysis.

Results Descriptive Analysis of Stress Levels of Parents

Descriptive analysis of the survey results showed that ninety participants (62.5%) had normal levels of stress, 11 participants (7.6%) had high levels of stress, and 43 participants (29.9%) had clinically significant levels of stress within the 90 percentile cut-off score (based on PSI4-SF scoring criteria) (see Table 2).

Table 2. Descriptive Analyses for Total Stress Levels and Demographic Variables (N=144)

	Total Stress Level n (%)				
	Normal level of	High level of	Clinically Significant level		
Demographic	Stress	Stress	of Stress	Total	
Characteristics	n (%)	n (%)	n (%)	n	
Gender					
Male	17 (68.0)	1 (4.0)	7 (28.0)	25	
Female	73 (61.3)	10(8.4)	36 (30.3)	119	
Marital Status					
Married	66 (63.5)	9 (8.7)	29 (27.8)	104	
Single	24 (60.0)	2 (5.0)	14 (35.0)	40	
Annual Family Income					
Less than \$50,000	12 (63.2)	0 (0.0)	7 (36.8)	19	
\$50,000-\$99,999	32 (62.7)	3 (5.9)	16 (31.4)	51	
\$100,00 or more	44 (62.0)	8 (11.3)	19 (26.7)	71	

There was a small difference between fathers and mothers regarding the percentage of participants with clinically significant levels of stress within each group. Among all participants, 28.0% of fathers and 30.3% of mothers had clinically significant levels of stress. Similarly, the percentage of participants with high levels of stress was higher among mothers (8.4%) compared to fathers (4.0%) (see Table 2). Among all participants, 40 were single, and 104 were married. The percentage of participants with clinically significant levels of stress was 35.0% among single participants and 27.9% among married participants. However, the percentage of participants with high levels of stress was higher among married participants (see Table 2).

The percentages of participants with clinically significant levels of stress decreased consistently when the annual family income increased. The percentage of participants with clinically significant levels of stress was 36.8% among participants with lowest income and was 26.7% among participants with highest income (see Table 2).

Results for Descriptive and Chi-Square Test of Independence Analysis Regarding the Association between Stress Levels of Parents and Coping Strategies They Use

The statistical association between individual coping strategies used by parents of children with ASD and their stress levels was interpreted through hypothesis testing for the chi-square test of independence. The results demonstrated that six of 13 coping strategies had a statistically significant association with the stress levels of participants. These significant coping strategies were denial, instrumental support, behavioral disengagement, venting, humor, and self-blame (see Table 3).

Table 3. Chi-square Test of Independence Analysis

	Stress Levels				
Coping Strategies	Chi-square	df	<i>p</i> -Value *Significant	Contingency Coefficient (CC)	
Behavioral Disengagement	30.432	6	.000*	.422	
Self-blame	26.894	6	$.000^{*}$.401	
Humor	15.658	6	.009*	.326	
Venting	15.095	6	.011*	.315	
Instrumental Support	15.137	6	.012*	.308	
Denial	13.356	6	.019*	.307	
Positive Reframing	10.768	6	.071	.290	
Self-Distraction	11.52	6	.054	.274	
Planning	9.269	6	.109	.269	
Active Coping	10.410	6	.079	.268	
Emotional Support	5.126	6	.587	.183	
Religion	4.266	6	.652	.170	
Acceptance	1.647	4	.808	.128	

Behavioral Disengagement

The chi-square test of independence demonstrated that there was a statistically significant association between behavioral disengagement and stress levels of participants, χ^2 (6, N = 144) = 30,432, p<.001. The results of chi-square tests of independence and descriptive analysis demonstrated participants who used behavioral disengagement a great deal were more likely to have clinically significant levels of stress (see Table 3).

Self-blame

The chi-square test of independence demonstrated that there was a statistically significant association between self-blame and stress levels of participants, χ^2 (6, N = 144) = 26.894, p<.000. The results of the chi-square test of independence and descriptive analysis demonstrated participants who used self-blame a great deal were more likely to have clinically significant levels of stress (see Table 3).

Humor

The chi-square test of independence demonstrated that there was a statistically significant association between humor and stress levels of participants, χ^2 (6, N = 144) = 15.658, p=.009. The results demonstrated participants who used humor a great deal were more likely to have normal levels of stress (see Table 3).

Venting

The chi-square test of independence demonstrated that there was a statistically significant association between venting and stress levels of participants, χ^2 (6, N = 144) = 15.095, p=.011. The results of the chi-square test of independence and descriptive analysis demonstrated participants who used venting a great deal were more likely to have clinically significant levels of stress (see Table 3).

Instrumental Support

The chi-square test of independence demonstrated that there was a statistically significant association between instrumental support and stress levels of participants, χ^2 (6, N=144) = 15.137, p=.012. The results of the chi-square test of independence and descriptive analysis demonstrated participants who used instrumental support a great deal were more likely to have normal levels of stress (see Table 3).

Denial

The chi-square test of independence demonstrated that there was a statistically significant association between denial and stress levels of participants, χ^2 (6, N = 144) = 13.35, p=.019 (see Table 3). The results of the chi-square test of independence and descriptive analysis demonstrated participants who used denial a great deal were more likely to have clinically significant levels of stress.

Discussion

PSI and its shorter versions are the most widely used inventory to evaluate stress levels in parents of children with ASD (Hayes & Watson, 2013). It is important to note that, the threshold used to determine higher levels of stress and clinically significant levels of stress were not uniform among the studies that used PSI and its shorter versions (Abidin, 1995; Strauss et al. 2012; Derguy, 2016). For example, the cut-off point for total row score of higher levels of stress was stated as 106 (81 percentile or above) for PSI-SF, but it was stated as 110 (85 percentile) for the fourth edition of PSI-SF (PSI4-SF) (Abidin, 1990; Abidin 2012). This non-uniformity might explain the variation in the literature regarding the rate of parents of children with ASD with clinically significant levels of stress. These rates were reported as 47.8% by Miranda et al. (2015), %34 (%42 mothers, %27 fathers) by Derguy et al. (2016), and 60% by Brei et al. (2012) in the literature. Findings of this study are consistent with the literature regarding rates of parents of children with ASD with clinically significant levels of stress that was found as 29.9% (N=43) based on 90 percentile cut-off score. This rate is relatively smaller compared to other studies in the literature but still pretty high when compared to rates of parents of typically developing children with clinically significant levels of stress indicated in literature as 8% by Keenan et al. (2016) and 17% by Baker-Ericzén, (2005).

The differences in the literature regarding rates of parents of children with ASD with clinically significant levels of stress might be because of different factors such as social income, or parental age. Considering the minimum yearly wage in the USA, approximately \$15.100 based on federal reports from (https://www.minimum-wage.org/federal,), majority of participants of this study were getting way higher than minimum wage (36% of participants get more than \$50.000 and 50.3% of participants get more than \$100.000\$) (see Table 2). Thus, compared to literature, the lower rate of participants with clinically significant levels of stress in this study might be because of relatively higher levels of income. İn addition, the lower rate might be explained with high average age (M=45) in this study. Older parents might have lower levels of stress since they could possibly have more experience of having a child with ASD compared to younger parents. However, the further research also should focus on age of parents when their child first diagnosed with ASD because even older parents might have stress levels of parents as high as younger parents since when their children diagnosed first.

Behavioral Disengagement

Behavioral disengagement is described as giving up when trying to deal with a situation (Carver, 1997). People may give up either when they do not have any hope for a solution to problems they face or when they do not know how to deal with the problems. Results of the present study demonstrated that there is a statistically significant association between stress levels of parents and behavioral disengagement.

Two factors could be attributed to why parents use behavioral disengagement although it is associated with higher levels of stress. First, parents may not know that using behavioral disengagement can exacerbate their stress levels, making it even harder for them to address the needs of their child. Second, parents may not know how to address the needs of their child with ASD, and as a result may resort to behavioral disengagement. Therefore, to prevent the parents from using behavioral disengagement, parents can be educated on interventions that support family

literacy, parenting practices and skills (Macklem, 2014). Schools might be an important resource for parents regarding how they can involve in parents support groups, where and how they can learn effective treatment interventions to implement for their children.

Self-blame

Self-blame is described as criticizing oneself (Carver, 1997). The results of the present study demonstrated that there is a statistically significant association between stress levels of parents and self-blame. Similar to previous research (see Obeid & Daou, 2015), this study found that parents who used self-blame a great deal were more likely to exhibit clinically significant levels of stress and less likely to exhibit normal levels of stress.

Several factors could be attributed as to why parents use self-blame. First, parents' use of self-blame might be the result of their lack of knowledge and skills with respect to addressing challenging behaviors of their child with ASD. For example, parents' use of harsh discipline, lack of monitoring, and lower levels of involvement when interacting with their children can lead to an increase in aggressive behaviors of their children (Macklem, 2014). Therefore, parents might blame themselves for the increased aggressive behaviors. Educating parents and giving them tools to address challenging behaviors may prevent parents from blaming themselves.

Second, the use of self-blame might be the result of stigma associated with having a child with disability and lack of inclusion in society. Parents of children with ASD may not feel comfortable being in public with their child with ASD because they might be judged and criticized for the behaviors of their child. As a result, these parents tend to keep their child with ASD at home, especially if their child has a severe disability. As a result, this negative outlook of society may lead parents to blame themselves for having a child with ASD.

Humor

Humor is described as making light of a situation (Carver, 1997). Existing literature is inconsistent about the association between humor and the stress levels of parents. Lai et al. (2015) included humor in the positive coping strategy group, which was associated with lower levels of stress. Benson (2010) included humor in the emotion-focused coping strategy group, which was associated with higher levels of stress. The results of this study demonstrated that there is a statistically significant association between stress levels of parents and humor. Parents who use humor a great deal were less likely to have clinically significant levels of stress.

The inconsistent results in the literature regarding use of humor and stress levels might be the result of parents' understanding or interpretation of humor. If parents interpret humor as ignoring and making light of the challenges pertaining to the behaviors of their child with ASD, then humor may inadvertently prevent parents from addressing the challenges they face and consequently increase their levels of stress. On the other hand, if parents interpret humor as recognizing the challenges and dealing with them to help their child and family, then humor may motivate parents to learn more about effective interventions and coping strategies, and consequently decrease their levels of stress.

Venting

Venting is described as expressing negative feelings (Carver, 1997). Previous research has included venting in emotion-focused and distraction coping strategy groups that have been associated with higher levels of stress. The results of the present study demonstrated that there was a statistically significant association between stress levels of parents and venting. Parents who use venting a great deal were more likely to have clinically significant levels of stress.

Parents' perception of their own inadequacy to address the needs of their child may result in use of expressing their negative feelings instead of learning how to manage their child. Expressing negative feelings may provide temporary relief for parents, but may not necessarily help parents to cope with their stress in the long-term. Therefore, learning how to meet the needs of their children may change parents' perception of inadequacy.

Instrumental Support

Instrumental support was described as getting help or advice from other people (Carver, 1997). People usually ask for support either when they need support or when they are eager to learn. Benson (2014) included instrumental support in problem-focused coping strategies that is associated with lower levels of stress. The results of the present study showed a statistically significant association between stress levels of parents and instrumental support. Parents who use instrumental support a great deal were more likely to have normal levels of stress.

Parents can get support from various resources such as schools, parent support organizations, educators, related professionals, family members, and other parents of children with ASD. Schools and educators can provide professional support that includes providing resources for parents and teaching them strategies to use at home with their children. Furthermore, local and national professional organizations can help parents by providing opportunities to engage with each other and learn from their experiences.

Denial

Denial was described as refusing to believe the situation exists (Carver, 1997). Denial was also identified as the first step of grief by Kubler-Ross's stages of grief theory (Kubler-Ross & Kessler, 2005). The results of the present study demonstrated that there was a statistically significant association between denial and higher levels of stress. Accepting the child with a disability might take some time for the parents. Because the average of parents in this study were relatively higher (M=45), it was not surprising that denial was the least used coping strategy while acceptance was the most.

It might be typical for parents to deny having a child with ASD when their child is first diagnosed with the disability. Accordingly, they may not be motivated and willing to learn effective interventions and seek support from educators and professionals regarding how to address the challenges they face. Engaging these parents with schools and related organizations such as Autism Speaks may help them to accept the situation in which they find

themselves and learn interventions to deal with the challenges they face.

Limitations of the Study

This study has some perceivable limitations. First, small sample size of study participants limits the ability to generalize the finding of this study to a larger population of parents of children with ASD. In addition, the sample of this study included parents from only one state in the U.S. Hence, the findings of the study may not be generalized to parents of children with ASD in other states of the US. Furthermore, within this study, the number of parents with high levels of stress were low because of the small raw score range based on PSI-SF (e.g., only 11 parents out of 144). Therefore, there was not a consistent increase or decrease in the frequency of parents with high levels of stress regarding their use of coping strategies. Additionally, it is recommended that future studies use a mixed methods design in order to get a deeper picture of the association between parental stress levels and the coping strategies they use.

Conclusion

Parents of children with ASD experience higher levels of stress compared to parents of children with other disabilities and parents of typically developing children. To cope with their stress, parents use a multitude of coping strategies. However, not all coping strategies help alleviate stress. Results of this study demonstrated that six of the 13 coping strategies from Brief COPE had a statistically significant association with stress levels of parents. These six coping strategies were instrumental support, humor, self-blame, denial, venting, and behavioral disengagement. Parents who used instrumental support and humor were more likely to have normal levels of stress, while parents who used self-blame, denial, venting, and behavioral disengagement were more like to experience higher or clinically significant levels of stress. Since parents of children with ASD can use a multitude of coping strategies at the same time, it is important for professionals who work with these parents to inform and educate parents what coping strategies can help reduce stress and what coping strategies can inadvertently lead to increased levels of stress. Moreover, professionals such as teachers, counselors, and school administrations, who provide services to children with ASD, must make efforts to provide informal supports to parents whenever possible. Finally, parents must be encouraged to participate in parent support organizations that provide advocacy, education, and support to families of children with ASD.

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