

COPING, RESOLUTION AND ADVOCACY
IN PARENTS OF CHILDREN WITH AUTISM

by

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Abstract

Parents of children with Autism Spectrum Disorder (ASD) demonstrate changes in the strategies they use to cope with parenting stress, shifting from problem-focused to emotion-focused coping as their child ages (Gray, 2006). Once parents have resolved their child's diagnosis, they may manage their emotions through sharing social support with other families and engaging in advocacy activities. In this study, parents of children with ASD completed an online survey measuring stress, resolution of negative feelings associated with the disorder, coping strategies, and advocacy involvement. It was hypothesized that parents who were more resolved would use more adaptive, emotion-focused coping strategies and would demonstrate higher participation in advocacy groups. Findings indicated that resolution and emotional support were significant predictors of advocacy involvement and that parents who are more resolved experienced less stress than parents who were not.

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Coping, Resolution and Advocacy in Parents of Children with Autism

With the rates of autism growing substantially over the past couple of decades, (American Psychiatric Association, 2013) more and more parents are facing the sad truth of finding out their child has Autism Spectrum Disorder (ASD). Unlike other developmental disabilities, like Down Syndrome, autistic children are characterized by limited social interactions and communication (e.g., lack of eye contact and inability to develop appropriate relationships), lack of particular interests and repetitive and inappropriate behavior (American Psychiatric Association, 1994). Perhaps one of the most stressful symptoms of autism is the inability to understand and communicate emotion. It is not uncommon for parents of children with autism to wonder whether their child loves, or even likes, them. This could explain why parents of children with autism face more stress than parents of typically developing children (Sivberg, 2002) or children with Down syndrome (Dabroska & Pisula, 2010).

A stressor is a person-environment encounter that an individual appraises as threatening or anxiety evoking (Folkman & Lazarus, 1988). Any one stressor can have varying effects on different people, and individual differences may change the degree to which a stressor affects a person. Some people are very negatively affected, whereas others are hardly affected at all. When many stressors are present in an individual's life, they may be appraised as increasingly more stressful than if they had occurred in isolation. Thus, stressors have additive effects (Eckenrode, 1984).

Major life stressors have been defined by Holmes and Rahe (1967) as events that create the need for a significant life adjustment. Examples of major life stressors can include death of a loved one or the diagnosis of a serious or fatal illness. A diagnosis of

autism is an example of a major life stressor. Further, the severity of the diagnosis will impact stress levels as well. Since autism is a spectrum disorder, symptomatology is higher in some children than in others. Several studies have found that autism symptomatology is positively associated with parental stress levels (Lyons, Leon, Phelps & Dunleavy, 2010; Seymour, Wood, Giallo & Jellett, 2013). Children who have severe symptoms and engage in more violent and inappropriate behaviors induce more stress in parents. Children with milder symptoms, on the other hand, induce less stress in parents.

Aside from the general stress that is caused by rearing an autistic child, parents of children with autism must face additional stressors from daily life hassles. Hassles are of a lesser magnitude than major life stressors, but everybody experiences hassles, since they are practical problems that surface in everyday life (Kanner, Coyne, Schaefer & Lazarus, 1980). Remembering to administer pills or getting stuck in traffic on the way to a doctor's appointment are two examples of daily life occurrences that add stress to the lives of parents of a child with autism. As described by Hinkle (1974), minor stressors are often trajectories of the larger major life events. Daily life hassles may not cause large amounts of stress individually, or even be remembered a week after they have occurred, but when combined have additive stress effects on parents (Pillow, Zaurtra & Sandler, 1996), leading to maladaptive coping strategies.

Russell and Norwich (2012) further illustrate the stressors that parents of children with autism must face in terms of getting services for their children. Diagnosis of the child comes as a prerequisite for receiving services inside and outside of the school. This means parents must face the negative stigma (e.g. negative responses from the public) that is paired with an autism diagnosis. Qualitative results from Russell and Norwich

(2012) show that parents who have delayed seeking an autism diagnosis for their child have often not done so because they fear how the public will react to their child.

Additionally, obstacles implemented in school systems (such as a separate school diagnosis criteria) make it difficult for parents to get their disabled children the proper services (MacFarlane & Kanaya, 2009). These stressors serve as another source of daily stress in this particular parenting population.

Folkman and Lazarus (1988) have determined two ways that individuals deal with stressors, depending on how they are appraised. The first, problem-focused coping, involves making an active effort to change the nature of a stressor. This often occurs in situations appraised as those that can be changed through individual effort. Confrontive coping and problem-solving are two examples of problem-focused coping. Confrontive coping is characterized by forcefully making needs clear to people who have a direct influence (Folkman & Lazarus, 1988). Problem-solving involves identifying the source of the stress and implementing a strategy that will eliminate or change the stressor. An example of problem-solving could be reaching out to school services and making an appropriate academic plan for children who are struggling in school.

The second coping mechanism, emotion-focused coping, deals less with changing the nature of the stressor, but more with changing the ideas and emotions that are associated with the stressor. Emotion-focused coping occurs in stressful situations that individuals appraise as impossible or too difficult to change. They must then engage in coping that will change or alleviate their negative thoughts and feelings. Accepting responsibility, turning to religion and positive reappraisal are just three popular examples of emotion-focused coping. Individuals who accept responsibility tend to internalize and

believe that they are the cause of the consequences in their lives. Turning to religion involves relinquishing the stressor to the hands of a divine being. This can be done through organized church, meditation, or prayer. Positive reappraisal involves reinterpreting negative events in an individual's life by giving the event a positive meaning (Lazarus & Folkman, 1988). An example of positive reappraisal would be appreciating the unique knowledge gained from a negative life event, despite the event's immediate misfortune. Parents of children with autism often use positive reappraisal as a way to appreciate the experience they have had by rearing a child with autism and sometimes even use this experience to help others through sources like advocacy groups.

There has been controversy over the existence of a third coping strategy called avoidance-oriented coping. This strategy involves either distraction or social diversion, and is essentially defined as avoiding a stressor and the associated negative feeling (Endler & Parker, 1990). Individuals who use distraction often participate in or direct attention to other domains in life in order to avoid perseverating on the main stressor. Social diversion is the use of socializing in order to avoid dealing with a stressor. This could be through 'going out' or phoning a friend (Endler & Parker, 1990). Many believe that avoidance-oriented coping is merely a strategy included in the larger emotion-coping mechanism (Lazarus & Folkman, 1988; Gray, 2006), while others have claimed that it is a strong enough subgroup to stand on its own (Dabrowska & Pisula, 2010; Endler & Parker, 1990). Similar to emotion-focused coping, avoidance-oriented coping has been associated with using escape tactics to deal with emotions rather than directly with the stressor.

The efficacy of these coping strategies has been explored by documenting their associations with feelings of well-being, depression, anger and other factors. Emotion-focused coping strategies have been associated with lower levels of well-being and higher levels of depression and stress, whereas problem-focused coping has typically been associated with higher well-being and lower levels of stress and depression (Endler & Parker, 1990; Higgins & Endler, 1995). Avoidance-oriented coping and emotion-focused coping are both associated with higher stress and lower well-being, supporting the view that avoidance-oriented coping is a sub-category classification of emotion-focused coping.

When individual differences in reactions to stressors are considered, the literature indicates conflicting findings. For example, research on active disengagement, or ‘giving up’ on a goal, has generally supported the view that it is a maladaptive, emotion-focused coping strategy (Scheier, Weintraub & Carver, 1986); but in the event that a goal is too difficult to accomplish, it is adaptive to actively disengage as long as commitment to the goal is also relinquished (Wrosch, Scheier, Carver & Schulz, 2003). Relinquishing goals may be problematic for parents rearing a child with autism; the diagnosis cannot be changed, but parents may feel that relinquishing goals means abandoning their child’s needs. Religious coping has also shown mixed results in whether it is adaptive (Coulthard & Fitzgerald, 1999). Some findings indicate that religious groups provide positive social support and have positive effects on well-being, while other findings illustrate negative effects from putting problems in the hands of religion. These are just two of several examples of coping variability across stressors.

Lazarus and Folkman (1985; Skinner & Zimmer-Gembeck, 2007) indicate that when faced with a stressor, individuals are first very emotionally affected but then shift to a problem-focused method of dealing with the stressor. The typical switch from emotion-focused coping to problem-focused coping may occur when individuals realize that they can take control, change or eliminate a stressor rather than only deal with it emotionally.

The coping pattern exhibited by parents of children with autism may be different. Gray (2006) found that as their child gets older, parents shift from problem-focused coping to emotion-focused coping. Gray (2006) conducted a longitudinal study that measured coping strategies in parents of autistic children between the ages of 4-19 years (three quarters falling between the ages of 6-12 years). Parent's coping strategies were measured again 9 years later. In the first assessment, parents reported many problem-focused coping techniques, such as relying on treatment services and helpful respite services. In the second assessment, parents coped less through problem-focused techniques and more frequently through emotion-focused strategies, such as religion, philosophical perspectives and emotional reactions.

This general switch from problem-focused to emotion-focused coping has generated discussions about adaptive and maladaptive coping. Many studies have provided evidence that problem-focused coping is beneficial, associated with greater well-being and lower rates of depression and anger (MacDonald, 2011; Scheier et al., 1986). In contrast, emotion-focused coping has been associated with increased stress (Dabrowska & Pisula, 2010; Lyons et al., 2010; MacDonald, 2011) and more maladaptive coping. Therefore, it seems odd that parents of children with autism would

switch from a coping strategy associated with increased well-being to one that is associated with decreased well-being.

In order to determine a coping approach that is efficacious for parents of children with autism, Hastings, Kovshoff, Brown, Ward, Espinosa and Remington (2005) moved beyond a dichotomous model consisting of only problem-focused coping and emotion-focused coping, focusing instead on a factorial approach that identifies how clusters of coping strategies associate with well-being. Using the Brief COPE (Carver, 1997), Hastings et al. (2005) identified four factors comprising coping strategies employed by parents of children with autism. These four factors are active avoidance coping, problem-focused coping, positive coping, and religious/denial coping. Active-avoidance coping reflects attempts to avoid the stressor and its effects, and included strategies such as substance use, behavioral disengagement, self-blame and venting of emotions. The problem-focused coping factor reflects typical problem-focused coping methods like planning, active coping and seeking instrumental support. Positive coping deals with adopting positive emotion-focused methods such as humor and positive reframing. The last factor, religious/denial coping, was a mixed factor that included the strategies of both religion and denial. Benson (2009) replicated the study done by Hastings et al. (2005) and identified four similar reliable coping factors in mothers: Engagement coping, distraction coping, disengagement coping, and cognitive reframing coping (also called positive reframing or positive reappraisal).

Hastings et al.'s (2005) problem-focused dimension and Benson's (2009) engagement factor were the only factors that included problem-focused coping strategies, suggesting that problem-focused coping is characterized by only a few clear-cut

strategies and that parents rely heavily on the strategies based in dealing with emotions. Benson (2009) then investigated the relationship that these coping factors had with maternal outcomes (e.g. depression, anger and well-being). Distraction and disengagement coping were associated with increased maternal depression and anger. Cognitive reframing, in contrast, was associated with higher levels of maternal well-being. These results support an interpretation of adaptive versus maladaptive emotion-focused coping strategy factors in parents of children with autism.

Beyond Benson's (2009) findings, cognitive reframing has been shown to reduce stress in parents of children with other developmental disabilities (Glidden, Billings & Jobe, 2006). Cognitive reframing is a positive form of coping that allows parents to give a new meaning to their child's disorder and the effects it has on their lives (Glidden et al., 2006). Parents who use cognitive reframing often celebrate the accomplishments of their child, rather than focusing on their limitations.

In exploring reasons for the change from problem-focused coping to emotion-focused coping, it may be that parents are disheartened when they do not see an improvement in or remission of their child's symptomatology, despite their efforts to actively cope with the disorder. When parents do not see positive changes in their child, they may in a sense 'give up' on trying to cure or change the disorder and focus more deeply on the emotional tolls that it places on the family. Parents may engage in emotional strategies, like positive reappraisal, distraction coping, or even disengagement to forget about the negative consequences the disorder has brought into their lives.

The change in coping method may also be related to a decrease in available services for children with disabilities as they develop into adolescence. The change in

goals in Individualized Education Plans (IEPs) in schooling systems reflects this decrease in services (Kurth & Mastergeorge, 2010). Autistic children in elementary school receive more remedial services (e.g., occupational therapy); in comparison, autistic children in middle school received more support services (e.g., life skills training). With the decrease in available services and goals instituted by the school system, there may be less problem-focused coping opportunities for parents.

The third and most durable potential cause of the switch from problem-focused to emotion-focused coping may be a parent's acceptance of their child's disorder (Watchtel & Carter, 2008). The term acceptance has been used loosely when describing the ways in which people have 'come to terms' with their child's disorder, often assuming parents either have or have not accepted the disorder. It is not clear from research what "acceptance" means because the term has not been operationalized and then systematically explored. This vague conceptualization does not allow for more complex explanations of the ways in which parents overcome their negative feelings about their child's disorder.

To illustrate, there may be cases where parents accept their child's disability and in turn seek out the proper services for their child. There could also be cases where parents accept the disability, but react in a negative way, creating the idea that there is nothing they can do to help their child and in turn denying them appropriate services. Alternatively, parents may accept their child, but not the disability, or possibly even reject their child because of the disability. The multiple dimensions of the term 'acceptance' complicate its immediate meaning and function.

Different views of acceptance create the need for a more specific construct that rules out the confusion of possibly accepting either the child or the disorder but not accepting the other. Resolution is a more specific term that is characterized by the overcoming of grief and other negative feelings associated with receiving a diagnosis (Marvin & Pianta, 1996). Marvin and Pianta (1996) created a measure called the Reaction to Diagnosis Interview (RDI) to determine whether or not parents have emotionally resolved their child's diagnosis. In the interview, parents answer questions on their feelings about the disorder and how the disorder affects their lives. Their answers are reviewed and then scored qualitatively by multiple readers. The phrases and responses used by parents can also be converted into a numerical score that measures the extent to which they have or have not resolved their child's disability. For example, a parent who says, "I no longer feel like I've lost a child because I am now more focused on their accomplishments," would be rated as more resolved than a parent who says "the pain gets worse every day because I am not seeing any improvements". Thus this measure addresses the multiple issues that are associated with the undefined use of 'acceptance' while creating a clear distinction between who is resolved and unresolved.

If the shift from problem-focused coping to emotion-focused coping in the parents of children with ASD is associated with resolution, parents should also be better attuned to the needs of their children. Wachtel and Carter (2008) found that mothers of children with autism who were resolved (according to the RDI) demonstrated more cognitive engagement and supportive engagement in childhood play interactions. This may suggest that along with coping, resolution of their child's disorder plays an important role in adaptive parenting and happiness. Poon, Koh and Magiati (2013) found that parents tend

to cater more to their child's satisfaction and happiness in adult years. Parents took surveys rating types of goals they viewed as important and likely to occur as their children grew up and reached adulthood. Results showed that parents valued outcomes relating to their child's satisfaction and safety over social participation and other typically valued outcomes, such as getting married or attaining higher education. While this study did not assess parent's resolution of their child's disorder, it seems that as the child grows older, parents place a higher value on their happiness as opposed to their 'normalcy' in society, which is consistent with the resolution construct.

When considering a transition from problem-focused coping to emotion-focused coping, it appears that parents are set up for failure in terms of adaptive coping. Many studies fail to identify the existence of particular adaptive emotion-focused coping strategies, such as positive reappraisal, and instead only focus on the general positive correlation between emotion-focused coping and increased stress. It may be, however, that resolution is the key ingredient for adaptive emotion-focused coping in the population of parents of children with autism. Higher levels of resolution of their child's disorder may differentiate those parent's who adaptively use emotion-focused coping from those who do not.

One support mechanism not addressed in studies of coping is the use of social support. Recent research has suggested that social support is an effective coping strategy for parents of children with diagnosed developmental disorders (Macdonald, 2011). Social support is defined as individuals or groups that provide assistance to help others combat life stressors. It has been identified in two forms: formal support and informal support (Schilling, Gilchrist & Schinke, 1984). Formal support is provided by

professionals such as doctors and psychologists and consists of information and less personal support. Informal support, in contrast, is provided by close friends and family members and consists of things such as friendship and respite services for parents. Access to informal support is associated with decreased stress (Hastings & Johnson, 2001; Tehee, Honan & Hevey, 2009). This illustrates the importance of close social networks in various groups of people dealing with stress. Social support as a coping strategy contains elements of both problem-focused and emotion-focused coping. When seeking instrumental support from health professionals, the support is being used in a problem-focused manner; however, seeking emotional informal support from family and friends involves more emotion-focused coping. It also may be that individuals who are more resolved may use these informal support systems more often to help reduce their stress.

As opposed to seeking social support there have been several studies focused on the effects that providing social support to others has on stress and well being. Brown, Nesse, Vinokur and Smith (2003) found that providing instrumental support to friends and family increases longevity. Warner, Shuz and Wurm (2010) found that providing support positively predicted quality of life in older patients with multiple disabilities. Parents of children with autism often participate in social groups that allow them to feel a sense of normalcy among others with similar situations (Schilling et al., 1984).

This exchange of support and information may be found in online support groups. Online support groups are particularly appealing to many groups of people suffering similar stressors, and provide an alternative or supplement to the informal support of close friends or family. Many people, including parents of children with autism,

participate in these online groups to discuss problems and to provide social support to each other (Mickelson, 1997). This may be due to the anonymity of online groups, which allows parents to avoid the shame of a diagnosis (White & Dorman, 2001).

It is interesting to note, however, that research has not explored the provision of support as a form of advocacy, despite the existence of many advocacy groups associated with various disorders. Perhaps advocacy is an emotion-focused strategy that is used after parents resolve their child's disability. Advocacy is commonly known as group support for a particular cause (Scotch, 1988). It exists in many different situations, whether it be autism awareness or advocacy for certain legislative laws to be passed in government; Individuals with Disabilities for Equality and Acceptance and Autism Speaks are two such groups. Individuals with disabilities face many barriers to uniting into a social group (Scotch, 1988). Perhaps advocacy is an emotion-focused strategy that is used after parents resolve their child's disability.

One of the key points of the Individuals with Disabilities Education Act (IDEA) is that parents of children with disabilities are the designated advocates for their child's navigation through the special education system (Phillips, 2008). In other words, parents must provide a voice for a community that often cannot speak out for itself. While many papers focus on social movements in advocacy and their effectiveness in getting children the services they deserve, there have been very limited investigations on the effectiveness of advocacy participation on parental well being. In addition, there have been no studies that have explored whether advocacy may constitute a problem-focused or an emotion-focus coping strategy. Since parents engaging in advocacy often deal with scenarios that may directly affect their children, advocacy could be conceptualized as problem-focused.

On the other hand, parents may tend to feel emotionally relieved through advocacy participation. It seems that an argument can be made for both classification under problem-focused coping and emotion-focused coping.

One qualitative study by Wang, Mannan, Poston, Turnball and Summers (2004) examined family quality of life (FQOL) as an outcome of parental advocacy efforts. Two interesting themes were discovered when parents were asked about their perception of their advocacy efforts. One theme was that advocacy was an obligation, such that they were involved because they had to be. The second theme was that their participation in advocacy groups was used as a mean to improve services. The study further examined responses by parents concerning their beliefs about the impact advocacy involvement has had on their lives. Three new themes were discovered: (1) advocacy enhances coping, (2) advocacy involves adversarial struggles and (3) advocacy causes stress. While the last two themes suggest a negative impact, the idea that advocacy may enhance the ways in which parents cope is also apparent in this research. Further, Nachshen and Jamieson (2000), report that parents who perceived advocacy as a challenge also perceived increase stress and decreased FQOL as a result of involvement, whereas parents who viewed advocacy as a coping strategy perceived lower stress and increased FQOL.

Many parents in Wang et al.'s (2004) study who reported their advocacy involvement enhanced coping also described the positive skills they had developed, such as being assertive and gaining self-confidence, through their advocacy activities. Parents also described the benefits of expanding their social support network through advocacy involvement. These two positive outcomes from advocacy (positive reappraisal and

social support) are the same adaptive emotion-focused coping strategies that have been associated with lowered stress and higher well-being in prior research on coping.

Advocacy, as a coping strategy among parents of children with autism, could arguably be made up of both positive reappraisal and the exchange of social support (seeking and providing social support). Extant research has not operationalized advocacy in this way. Since both of these coping strategies have been associated with well-being and decreased stress (Glidden et al., 2006; Hastings et al., 2005) it seems that a case could be made for these same positive effects stemming from advocacy involvement, and may explain why many parents participate in such groups. If advocacy provides both social support and opportunities for positive reappraisal, parents who reportedly participate in advocacy groups should also report coping through the exchange of social support and positive reappraisal. If this is the case, this conceptualization of advocacy may account for the shift from problem-focused coping to emotion-focused coping in parents of children with autism. Finally, and most importantly, it also follows that parents who engage in the use of adaptive, emotion-focused strategies should also have resolved their grief associated with their child's disorder. If all three components (positive reappraisal, social support and resolution) are associated with advocacy involvement this may mean that positive reappraisal and social support may have to be reconceptualized as possible problem-focused methods of coping.

The current study investigated the following hypotheses: (1) parents who scored high on a measure of resolution would cope through positive reappraisal and through social support, which, if supported, would suggest that parents who were more resolved cope using adaptive emotion-focused strategies; (2) parents who scored high on a

measure of advocacy would cope through positive reappraisal and social support, which, if supported, would suggest that advocacy involvement is associated with adaptive emotion-focused strategies; (3) use of social support, use of positive reappraisal and resolution together would predict and identify the variance in advocacy involvement.

Methods

Participants

Seventy-one participants were recruited through local Special Education Parent Teacher Advisory groups, advocacy efforts, mailing lists, online Facebook groups, and word of mouth (the survey also included a message at end that requested that participants forward the link to other people they felt would appropriately fit the criteria for the study). Six participants who were either not parents or guardians of children with autism or who did not have a child with either autism, Aspergers or Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS) were omitted from the data analysis. Of the remaining 65 participants, 60 were mothers, 4 were fathers and 1 was a female legal guardian and all of children were diagnosed with either Autism, Aspergers syndrome, or PDD-NOS. Parents were primarily Caucasian (87.7%) and had at least some college education (89.2%). The majority of parents were either married or living with their partner (89.2%).

Materials

Demographics. The demographic questionnaire requested information about the parent and child's location, gender, age and ethnicity. The questionnaire addressed questions about participants' home life, marital status and about their child's diagnosis. See Appendix A for a copy of this measure.

Stress. Participants answered five questions about the stress they experienced associated with raising a child with autism. Each question allowed participants to respond on a Likert scale from 1 (not very true of me) to 5 (very true of me). Individual item responses were summed to generate a score for stress (see Appendix A).

Coping. Specific coping strategies were measured by using the Brief COPE (Carver, 1997). This is a self-report questionnaire used to assess a number of different coping behaviors people use in specific situations. It is made up of 14 subscales: self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion and self-blame. Participants read a series of statements asking them to rate these strategies (two items for each subscale) from 1 (“I haven’t been doing this at all”) to 4 (“I’ve been doing this a lot”). Scores on each subscale were calculated by averaging the item ratings. Internal reliabilities for the 14 subscales range from $\alpha=0.57-0.90$ (Carver, 1997), and similar results have been found with a population of parents of children with ASDs ($\alpha=0.54-0.93$) (Benson, 2009). The wording was modified to accommodate the stressors associated with ASDs. See Appendix B for a copy of this measure.

Resolution. Using the coding system from the Reaction to Diagnosis Interview (RDI), created by Marvin and Pianta (1996) a 12-question survey was created. Six of the questions were targeted to reflect signs of resolution, and six of the questions were targeted to reflect non-resolution, and elicited responses concerning parents’ memories and feelings about their child’s medical problems. Participants responded to the questions on a scale of 1 (this is not true of me) to 5 (this is very true of me). This survey,

rather than classifying parents as either resolved or non-resolved, provided a score based on summed ratings. See Appendix C for a copy of this measure.

Advocacy Involvement. Participants completed five items that assessed their advocacy involvement. Questions targeted their opinions of advocacy, their use of advocacy as a form of social support, their use of advocacy as a form of positive reappraisal and the degree to which they relied on and used advocacy groups. Each question allowed participants to respond with either “Yes”, “Somewhat”, “No”, or “N/A”. Scores were generated by assigning a value of one to three to participants’ responses, and then averaging the responses. Higher scores indicate higher advocacy involvement. See Appendix D for a copy of this measure.

Procedure

Participants received an email containing a link to the online survey. Before the survey began, participants read a brief explanation of the positive benefits of participating in the study. They then provided their electronic signature on an informed consent prompt (see Appendix E for the consent form). The survey began and participants were asked to answer all the questions fully and to the best of their ability. Upon completion of the survey, participants were provided with contact information if they had any further questions about the results of the experiment and were asked to pass the link to the survey on to other parents who they thought might be well fit for the study.

Design

This study utilized a correlational design and investigated associations between positive reappraisal, social support, resolution and advocacy. A regression analysis was

conducted to investigate the relationships among these variables, and gain insight into what may contribute to variance in advocacy.

Results

Descriptive statistics regarding stress, coping strategies, resolution and advocacy can be found in Table 1. Parents, on average, fell close to the midline of the stress measure, which spanned from 5 – 25 ($M = 16.20$, $SD = 5.23$). With respect to resolution, parents generally scored well above the midpoint of the resolution measure ($M = 48.94$, $SD = 6.80$), which spanned from 5 - 65. The most frequently used coping strategy was Acceptance ($M = 3.34$, $SD = .62$), followed by Active Coping ($M = 2.94$, $SD = .90$) and Planning ($M = 2.86$, $SD = .95$). Denial ($M = 1.06$, $SD = .21$), Substance Use ($M = 1.30$, $SD = .58$) and Behavioral Disengagement ($M = 1.30$, $SD = .45$) were the least frequently used coping strategies. Parents, on average, scored above the midpoint on the advocacy measure (spanning from 1 – 3); however there was not much variability among the scores ($M = 2.24$, $SD = .59$).

To test the first two hypotheses, investigating whether resolution and advocacy were associated with positive reappraisal and social support, correlations were calculated between stress, coping strategies, resolution and advocacy. The entire set of correlations can be found in Table 2 and 3. Table 2 displays the correlations between stress, resolution, advocacy, problem-focused coping strategies and adaptive emotion-focused coping strategies. Table 3 displays the correlations between stress, resolution, advocacy and maladaptive emotion-focused coping strategies. Neither resolution nor advocacy were significantly correlated with positive reframing, emotional support or instrumental support. Thus, the first two hypotheses were not supported. Resolution was positively

correlated with the Acceptance measure on the Brief COPE $r(62) = .29, p = .02^1$, which suggests validity of the created resolution measure, since the Acceptance strategy in the Brief COPE similarly involves resolving the negative emotions associated with an event. Further, resolution was negatively correlated with stress $r(63) = -.51, p = .0001$ such that parents who were more resolved experienced less stress. Resolution was also inversely correlated with several maladaptive coping strategies measured in the Brief COPE, such as denial $r(63) = -.31, p = .01$, venting $r(63) = -.33, p = .01$ and self-blame $r(63) = -.28, p = .02$, such that parents who were more resolved coped less through these strategies.

To address the third hypothesis, a regression analysis was conducted using advocacy as the dependent variable and stress, positive reframing, emotional support, instrumental support and resolution as the predictor variables. The regression approached significance $R^2 = .16, F(5, 59) = 2.14, p = .07$. The contribution of each independent variable to advocacy involvement can be found in Table 4. Examination of the beta weights suggests that resolution ($p = .03$) and emotional support ($p = .03$) were the strongest predictors of advocacy. Parents of children with autism who were more resolved and coped less through emotional support were more likely to participate in advocacy groups. In addition, instrumental support was marginally predictive of advocacy involvement ($p = .10$), such that parents who coped through instrumental support were more likely to participate in advocacy efforts. Stress and positive reappraisal were not significant predictors of advocacy involvement.

¹ Degrees of freedom reflect the number of participants who provided data on the Acceptance measure in the Brief COPE

Discussion

The current study was designed to investigate a conceptualization of advocacy as a coping strategy for parents of children with autism. Previous research suggests that advocacy participation may be comprised of positive reappraisal, social support and resolution of the negative feelings associated with the diagnosis (Hastings & Johnson, 2001; Glidden et al., 2006). Past research has not explored advocacy efforts as a potential coping strategy.

The findings of this study showed that resolution and emotional support were predictive of advocacy involvement. Parents who were more resolved and coped less through emotional support were more likely to participate in advocacy. Interestingly, emotional support was not originally hypothesized to be predictive of advocacy in this way. If increased emotional support is associated with less advocacy engagement, it may be that parents are not actually turning to these groups for emotional support at all. Instrumental support, in contrast, was associated with advocacy involvement. It may be that the type of support parents obtain through advocacy participation is more information based, as opposed to support similar to that of a friend or family member. The goal of many advocacy groups is to spread information and to provide a supporting community through things like fundraisers, activities and meetings (Scotch, 1988) so it is unlikely that people in advocacy groups are looking for emotional bonds with the people they meet, since the main purpose of advocacy groups is to raise public awareness of their cause. While parents who are more resolved may not need the emotional support, they may still identify with parents who do. Advocacy participation is an effective way

for these parents who provide assistance to parents who are going through a similar situation.

Since acceptance is a construct that has remained undefined in the literature and resolution is a construct that has not been frequently studied in research, this investigation of resolution as precursor for adaptive coping is important. Findings of this study are consistent with the hypothesis that resolution has positive effects for parents of children with autism. There was no evidence that resolution was associated with the predicted adaptive coping strategies – positive reappraisal, emotional support or instrumental support; however, resolution was negatively associated with several maladaptive coping strategies- denial, venting and self-blame. Although these findings do not support the hypothesis that resolution is associated with adaptive coping, it does seem that resolution is an important factor for the prevention of maladaptive coping. Because resolution was associated with a reduction in stress, parents may decrease their likelihood of engaging in strategies that will harm their well-being. This suggests that developing resolution may be a useful intervention strategy for people who are currently engaging in maladaptive coping strategies and who wish to ease away from these harmful strategies.

Several methodological issues may have contributed to weak support for this study's hypotheses. First, a larger, more diverse sample may have been needed. The majority of the sample was female Caucasians, with at least some college education. It may be that certain demographic characteristics either facilitate or hinder access to advocacy groups, and may even have an effect on parents coming to resolution of their child's diagnosis. For example, parents without a college education may not have available information about the existence of advocacy groups. They also may not know

how to utilize effective coping strategies. By collecting a larger, more diverse sample these issues could be addressed. Second, advocacy was measured with five questions, which only spanned across a three-point scale (responses of N/A were not included in the calculation of advocacy). If more items were included on this measure and if the scale was increased to a five points, there may have been more variance in the scores. Finally, past studies have shown that autism symptomatology is significantly correlated with parental stress (Lyons et al., 2010; Seymour et al., 2012). It may be that parents of low-functioning children cope differently than parents of higher-functioning children. Parents of children with low-functioning autism may experience a longer and more difficult process of coming to resolution than parents of children with symptoms that are less severe. Further, parents of children with low-functioning autism may avoid acknowledgement of their child's disability, keeping them from both resolution and advocacy. Future studies should assess autism severity in order to investigate the role that it plays in levels of advocacy involvement, as well as its association with resolution and various coping strategies.

The findings of this study support those reported in the literature in identifying resolution as a key factor in a shift towards increased well-being in parents of children with autism. This relationship warrants continued investigation of the process by which parents come to resolution. Greater understanding of resolution may provide the basis for more effective therapies and interventions for parents of children with autism in order to help them adaptively cope, and perhaps even encourage them to join active advocacy groups.

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Appendix A: Demographic Questionnaire

Today's Date: ____/____/____
 Month Day Year

1. What year were you born?
2. What is your gender?
 - Male
 - Female
3. Which racial group best describes your family?
 - American Indian or Alaskan Native
 - Specify _____
 - Asian
 - Specify _____ (e.g., Chinese, Korean, Indian)
 - Black or African American
 - Hispanic or Latino/a
 - Specify _____ (e.g. Mexican, Cuban)
 - Native Hawaii and/or Pacific Islander
 - White or Caucasian
 - Other
 - Specify _____
 - More than one race
 - Specify _____
4. What is the highest grade in school that you completed?
 - Some high school
 - Completed high school or GED
 - Vocational, technical, trade, or business school beyond the high school level
 - Some college, but no degree
 - Associate degree
 - Bachelor's degree
 - Some graduate school
 - Master's degree
 - Doctorate degree
5. What is your marital status?
 - Married or living with partner
 - Single - never married
 - Divorced - not remarried
 - Widowed - not remarried

The following questions are about your child with an autism spectrum disorder. If more than one of your children has an autism spectrum disorder, please answer these questions for the child whose name comes first alphabetically.

6. What is your relationship to your child?

- Biological mother
- Biological father
- Adoptive mother
- Adoptive father
- Legal guardian
- Specify _____

7. What is your child's date of birth? :

____/____/____
Month Day Year

8. What is your child's gender?

- Male
- Female

9. Does your child live with you _____?

- Full time
- Part time
- None of the time

10. What diagnosis has your child received?

- Autistic Disorder
- Asperger Syndrome or Asperger's Disorder
- Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)

11. Who diagnosed your child?

- Physician/Medical doctor
- Psychologist
- Educational professional
- Specify _____
- Other
- Specify _____

12. How old was your child when he or she received a diagnosis: _____

13. What is your child's placement in school?

- Public school - regular education classroom (mainstreamed)
- Public school - special education classroom

- Public school - a mixture of regular and special education classes
 - Private school - regular education classroom
 - Private school – special education classroom
 - Private school – a mixture of regular and special education classes
 - Home school
 - Other
- Specify _____

14. What grade is your child currently in? : _____

15. What interventions has your child received in the past year or your child is currently receiving? Please indicate all that apply.

- Applied Behavior Analysis (ABA) therapy
 - Speech therapy
 - Occupational therapy
 - Physical therapy
 - Social skills intervention
 - Other- please list any not mentioned above
-

16. What is your annual household income:

- Less than \$35,000
- \$35,000 - \$49,999
- \$50,000 - \$74,999
- \$75,000 or above
- Prefer not to respond

17. Do you receive additional financial coverage or funding for your child's needs and services? Please select all that apply:

- Private health insurance
 - Medicaid only
 - Medicaid Waiver
 - Other
- Specify _____

18. Which of the following do you rely on for support? Please select all that apply:

- Support Groups
- Counseling Services
- ASD services
- School Staff
- Pecialized Physicians

- Spouse
- Children
- Brothers/sisters
- Parents
- Other: please specify _____

For the following questions please rate how true these statements are to you. (1 meaning “this is not very true to me” and 5 meaning “this is very true about me”)

19. I often feel overwhelmed by the stress associated with raising a child with autism.

1 2 3 4 5

20. I often feel frustrated because I have a child with autism.

1 2 3 4 5

21. The stress that I feel often distracts me from daily life.

1 2 3 4 5

22. I would say I am more stressed than the average parent.

1 2 3 4 5

23. My close friends and family have made comments/identified that I feel stressed.

1 2 3 4 5

Appendix B: Brief COPE

- 1 = I haven't been doing this at all
- 2 = I've been doing this a little bit
- 3 = I've been doing this a medium amount
- 4 = I've been doing this a lot

- 1. I've been turning to work or other activities to take my mind off things.
- 2. I've been concentrating my efforts on doing something about the situation I'm in
- 3. I've been saying to myself "this isn't real".
- 4. I've been using alcohol or other drugs to make myself feel better.
- 5. I've been getting emotional support from others.
- 6. I've been giving up trying to deal with it.
- 7. I've been taking action to try to make the situation better.
- 8. I've been refusing to believe that it has happened.
- 9. I've been saying things to let my unpleasant feelings escape.
- 10. I've been getting help and advice from other people.
- 11. I've been using alcohol or other drugs to help me get through it.
- 12. I've been trying to see it in a different light, to make it seem more positive.
- 13. I've been criticizing myself.
- 14. I've been trying to come up with a strategy about what to do.
- 15. I've been getting comfort and understanding from someone.
- 16. I've been giving up the attempt to cope.
- 17. I've been looking for something good in what is happening.
- 18. I've been making jokes about it.
- 19. I've been doing something to think about it less, such as going to the movies, watching TV, reading, daydreaming, sleeping or shopping.
- 20. I've been accepting the reality of the fact that it has happened.
- 21. I've been expressing my negative feelings.
- 22. I've been trying to find comfort in my religion or spiritual beliefs.
- 23. I've been trying to get advice or help from other people about what to do.
- 24. I've been learning to live with it.
- 25. I've been thinking hard about what steps to take.
- 26. I've been blaming myself for things that happened.
- 27. I've been praying or meditating.
- 28. I've been making fun of the situation.

Appendix C: Modified RDI Resolution Survey

Please answer on a scale of 1 – 5 how applicable the following situations are to your life, 1 meaning ‘this does not often occur’ and 5 meaning ‘this is very true of me’.

1. Knowing that my child has autism is still difficult for me to accept.
2. The goals I have for my child are now geared more towards my child’s happiness
3. I am now more able to do things that I enjoy.
4. I often wonder “why me?” or “why my child?” when thinking about my child’s medical problems.
5. I believe that one day my child will be able to live as normal a life as anybody else.
6. I am now more familiar with the benefits and drawbacks of raising a child with autism.
7. Although my child has been diagnosed with autism, I feel that he/she is capable of doing just about anything a normal child can.
8. I spend a lot of time thinking about why this has happened to my child.
9. I often relive the day that I found out that my child has autism.
10. While my child lacks in certain areas, he/she does have many special qualities.
11. It is hard for me to explain my feelings about my child and how the diagnosis of autism has affected my life.
12. I often struggle to articulate or remember what it was like to find out that my child has autism.
13. I feel sad much of the time when thinking about my child.
14. What I expect of my child has changed since he/she was diagnosed with autism.

Appendix D: Advocacy Involvement

Please select the appropriate responses.

1. Do you consider yourself an advocate for the cause of autism?
Yes Somewhat No N/A

2. Do you feel close to people you've met through advocacy/support groups?
Yes Somewhat No N/A

3. Do you feel that becoming involved in advocacy groups is a positive event that you have experienced in light of a negative situation?
Yes Somewhat No N/A

4. Do you feel like a group that you are a part of has made a difference (whether it be in the school system, government, your child's well-being)
Yes Somewhat No N/A

5. Have you ever recruited other parents of children with autism or other developmental disabilities to join an advocacy or support group?
Yes Somewhat No N/A

Appendix E

Consent Form for Online Survey

Research on Coping in Parents of Children with Autism

With the rates of autism growing over the past couple of years, many services, support groups and advocacy organizations have surfaced to assist parents of children with autism. Parents have many different ways of coping with the stress that often comes along with raising a child with autism. The goal of the current research is to assess the different coping methods used by parents of children of autism and to examine the associations that they may have with each other and stress and well being in parents.

First, you will be asked some general questions about yourself and your child. Then you will be asked some questions about different coping strategies that you may or may not use in dealing with the stress that comes with raising an autistic child. Then you will be asked to answer some questions about the feelings you have, associated with raising an autistic child. Finally you will be asked 5 questions about your involvement in autism advocacy groups. There are no known risks involved in participating in this study. Your participation is voluntary and you may skip any question that you do not want to answer. Your responses are confidential; they will be coded by number and combined with the results of the other participants in the analysis of the results. It is our hope that this information could add to the research on adaptive and effective coping strategies used in parents of children with autism.

The questionnaire should take about 10 minutes to complete. Upon completing the questionnaire, we ask that if you know any other parent of a child with autism who may be willing to fill out this questionnaire that you email them the link of this survey.

For more information about this study you can email us:

Scott-t.brown@purchase.edu

Peggy.decooke@purchase.edu

By clicking this link, I certify that I have read the above description of the study and that I am 18 years of age or older. I understand that I may contact the Chair of the Human Subjects Committee if I experience any problems during this experiment or have concerns about the ethics of this research (914)251-6645 or meagan.curtis@purchase.edu.

[Click here to begin.](#)

Table 1

Descriptive Statistics for Stress, Coping, Resolution and Advocacy

<u>Variable</u>	<u>Mean</u>	<u>SD</u>
Stress	16.20	5.23
Active Coping	2.94	.90
Planning	2.86	.95
Positive Reframing	2.62	.95
Acceptance	3.34	.62
Humor	1.79	.91
Religion	1.99	1.07
Emotional Support	2.28	.86
Instrumental Support	2.49	.84
Self-Distraction	2.26	1.01
Denial	1.06	.21
Venting	1.85	.74
Substance Use	1.25	.58
Behavioral Disengagement	1.25	.45
Self-Blame	2.12	1.01
Resolution	48.94	6.80
<u>Advocacy</u>	<u>2.24</u>	<u>.58</u>

Table 2

Correlations between Stress, Resolution, Advocacy and Problem-Focused and Adaptive Emotion-Focused Coping Strategies

Variable	1	2	3	4	5	6	7	8	9
1. Stress									
Pearson <i>r</i>	—	-.51**	-.03	.33**	.30*	.15	-.22	.08	.17
Sig.		(.001)	(.85)	(.01)	(.02)	(.23)	(.08)	(.52)	(.15)
2. Resolution									
Pearson <i>r</i>	—	—	-.21	-.15	-.11	-.01	.29*	-.002	-.08
Sig.			(.09)	(.23)	(.38)	(.95)	(.02)	(.42)	(.52)
3. Advocacy									
Pearson <i>r</i>	—	—	—	-.10	-.19	-.14	-.17	.10	-.07
Sig.				(.41)	(.14)	(.25)	(.19)	(.42)	(.59)
4. Active Coping									
Pearson <i>r</i>	—	—	—	—	.58**	.41**	.36**	.41**	.37**
Sig.					(.001)	(.001)	(.003)	(.001)	(.002)
5. Planning									
Pearson <i>r</i>	—	—	—	—	—	.55**	.35**	.43**	.45**
Sig.						(.001)	(.004)	(.001)	(.001)
6. Positive Reappraisal									
Pearson <i>r</i>	—	—	—	—	—	—	.40**	.35**	.20
Sig.							(.001)	(.004)	(.12)
7. Acceptance									
Pearson <i>r</i>	—	—	—	—	—	—	—	.19	.11
Sig.								(.13)	(.12)
8. Emotional Support									
Pearson <i>r</i>	—	—	—	—	—	—	—	—	.67**
Sig.									(.001)
9. Instrumental Support									
Pearson <i>r</i>	—	—	—	—	—	—	—	—	—
Sig.									

*Correlation is significant at the .05 level (2-tailed).

**Correlation is significant at the .01 level (2-tailed).

Table 3

Correlations between Stress, Resolution, Advocacy and Maladaptive Emotion-Focused Coping Strategies

Variable	1	2	3	4	5	6	7	8	9	10	11
1. Stress											
Pearson <i>r</i>	—	-.51**	.03	.10	.11	.30	.28*	.40*	.01	.26*	.40*
Sig.		(.001)	(.85)	(.43)	(.39)	(.01)	(.03)	(.001)	(.88)	(.04)	(.001)
2. Resolution											
Pearson <i>r</i>	—	—	.21	.24	-.05	-.02	-.31*	-.33**	.05	-.19	-.28*
Sig.			(.09)	(.06)	(.70)	(.85)	(.01)	(.01)	(.67)	(.13)	(.02)
3. Advocacy											
Pearson <i>r</i>	—	—	—	.11	.09	-.07	-.13	.02	-.07	-.07	.44
Sig.				(.41)	(.48)	(.60)	(.30)	(.89)	(.56)	(.56)	(.73)
4. Humor											
Pearson <i>r</i>	—	—	—	—	.21	.40**	.11	.42**	.27*	.15	.42**
Sig.					(.31)	(.001)	(.37)	(.001)	(.03)	(.25)	(.001)
5. Religion											
Pearson <i>r</i>	—	—	—	—	—	.04	.09	.30*	.27*	.07	.38**
Sig.						(.75)	(.46)	(.02)	(.03)	(.58)	(.002)
6. Self-Distraction											
Pearson <i>r</i>	—	—	—	—	—	—	.20	.28*	.26*	.15	.35**
Sig.							(.11)	(.02)	(.04)	(.25)	(.004)
7. Denial											
Pearson <i>r</i>	—	—	—	—	—	—	—	.16	.32**	.13	.27*
Sig.								(.19)	(.01)	(.31)	(.03)
8. Venting											
Pearson <i>r</i>	—	—	—	—	—	—	—	—	.16	.08	.41**
Sig.									(.19)	(.54)	(.001)
9. Substance Abuse											
Pearson <i>r</i>	—	—	—	—	—	—	—	—	—	-.06	.38**
Sig.										(.65)	(.002)
10. Behavioral Disengagement											
Pearson <i>r</i>	—	—	—	—	—	—	—	—	—	—	.34**
Sig.											(.006)
11. Self-Blame											
Pearson <i>r</i>	—	—	—	—	—	—	—	—	—	—	—
Sig.											

*Correlation is significant at the .05 level (2-tailed).

**Correlation is significant at the .01 level (2-tailed).

Table 4

Beta Weights of Stress, Positive Reframing, Emotional Support, Instrumental Support and Resolution as Predictors of Advocacy

<u>Variable</u>	<u>Beta</u>	<u>Sig.</u>
Stress	.02	.35
Positive Reframing	.12	.12
Emotional Support	-.25*	.03
Instrumental Support	.19	.10
Resolution	.03*	.03

*Correlation is significant at the .05 level (1-tailed).