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Olivia F. Macdonald
University of South Florida

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Putting the Puzzle Together: Factors Related to Emotional Well-being in Parents of Children with Autism Spectrum Disorders

Olivia F. Macdonald

Honors Thesis

Department of Psychology

University of South Florida

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Major Professor: Judith B. Bryant, Ph.D.

Abstract

Autism spectrum disorders now affect 1 in 110 children. Thus, thousands of families are facing the unique challenges associated with raising a child with an ASD. The purpose of the current study was to investigate how parental well-being relates to coping strategies, social support, and isolation. Mothers and fathers were recruited through the email lists of autism organizations, and 221 parents completed an anonymous, online survey. A decrease in reported feelings of anxiety and depression with greater use of social support supported the literature on the beneficial role it has on emotional well-being. Analyses also suggested that informal sources of support might be particularly important. It was found that the greater parents' use of emotional-based coping was, the greater their reported feelings of depression and anxiety. Specific stressors and coping behaviors of these parents were also explored. Further investigation is needed to better understand the roles of parent involvement and different coping methods on parental emotional well-being in this population. Implications for ASD interventions are also discussed.

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Portions of these results have been presented at the American Association of Behavioral and Social Sciences (AABSS) Conference in Las Vegas on February 10, 2011, and USF's Undergraduate Research Symposium and Celebration on April 15, 2011.

Putting the Puzzle Together: Factors Related to Emotional Well-being in Parents of Children with Autism Spectrum Disorders

Recent figures released by the CDC (2009) show that autism spectrum disorders (ASDs) now affect 1 in 110 children. This means thousands of families are raising a child with an ASD and facing the unique challenges and experiences associated with it. These challenges can take a severe toll on a parent's mental well-being, as evidenced by the recent case of Gigi Jordan. She devoted her entire life to helping her son with Autistic Disorder, becoming obsessed with his treatment (Associated Press, 2010). Jordan eventually killed her son and attempted suicide after he failed to improve despite numerous interventions (Associated Press, 2010). Although this is an extreme case, it illustrates how severe an effect ASDs can have on the mental health of a parent. Researchers have begun to investigate a number of different factors involved, such as parenting self-agency, coping strategies, and social support.

In this paper, I briefly explain ASDs and their symptomatology before discussing family systems theory and how a child's disorder can impact a parent. Stress and depression are the two most common indicators used to measure parental, emotional well-being. (For the purpose of this study, stress was operationalized as anxiety). After looking at how stress and depression are expressed in this population, I examine some of the internal and external factors that seemed more likely to moderate the levels of stress and depressive symptoms. I chose the following factors to investigate in relation to stress and depressive levels based on the current literature, feedback from parents of children with ASDs, and Abidin's model of parenting stress (1976): coping strategies, social isolation, and social support.

Autistic Disorder, Asperger Syndrome, and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) are the developmental disorders that are generally considere to make up the autism spectrum. Autistic Disorder is characterized by delays and deficits in an individual's ability to interact socially (e.g., lack of eye contact, no emotional reciprocity, inability to have developmentally appropriate peer relationships) and communicate (e.g., little to no language, inability to maintain a conversation, echolalia), as well as atypical patterns of behavior (e.g., inflexible with changes in routine, hand flapping, abnormal obsessions with objects or parts of an object) (American Psychiatric Association, 1994). Symptoms are present before the age of three (American Psychiatric Association, 1994). Similar to children with Autistic Disorder, children with Asperger Syndrome have problems with social skills and the stereotyped, repetitive motor behaviors some children with Autistic Disorder have (American Psychiatric Association, 1994). However, children with Asperger Syndrome do not exhibit the significant delays in language development, as do children with Autistic Disorder.

They also have age-appropriate self-help skills and cognitive levels, normal curiosity about their environment, and, apart from socializing, adaptive behaviors (American Psychiatric Association, 1994). Children with PDD-NOS receive the diagnosis if they have pervasive and severe problems with social skills and communication or the stereotyped interests, activities, and behaviors that do not meet the criteria for another ASD, avoidant personality disorder, schizophrenia, or schizotypal personality disorder (American Psychiatric Association, 1994). PDD-NOS is often referred to as "atypical autism." Children with Asperger Syndrome or PDD-NOS usually have less severe symptomatology than those with Autistic Disorder (CDC, 2009). However, even two children who have been diagnosed with the same disorder can still have great variations in specific symptoms, strengths, and handicaps. Although Rett's Disorder and Childhood Disintegrative Disorder are also currently classified in the DSM as being part of the spectrum, these disorders are dissimilar to other ASDs in the presentation and duration of autistic symptoms. Rett’s Disorder is not being recommended for inclusion in DSM-5 due to the brevity of time a child has autistic symptoms (American Psychiatric Association, 2010). Children with Childhood Disintegrative Disorder have had a continuous period of normal development and behaviors before regressing, unlike children who have Autistic Disorder, Asperger syndrome, or PDD-NOS (American Psychiatric Association, 1994). The obvious complexity and nature of the spectrum have made it difficult to determine how to address the needs of individuals with these disorders, as well as the needs of those closest to them.

According to family systems theory, the child is not the only individual affected by an ASD. Within the larger family system, there are several sub-systems, such as the parent-child or marital relationship systems, which interact with one another (Gerson, 1995; Morgan, 1988). Children play a vital role in several subsystems and even influence the others they are not directly part of; this is true for children with an ASD (Morgan, 1988). In fact, they are likely to have a greater influence on their family members because of the demands and dependence on others who are associated with their disability. It is not unheard of for parents of children with ASDs, especially mothers, to experience burnout (Milgram & Atzil, 1988), for families to experience loneliness and isolation, and for parents to sacrifice their needs at least partially due to the responsibilities of raising a child with this disability (Morgan, 1988). However, it is still not well understood exactly how and why ASDs impact a family and its members.

One effect that has been very consistently found is that parents of children with ASDs experience higher levels of stress and depressive symptoms than parents of neurotypical children (Dumas, Wolf, Fisman, & Culligan, 1991; Sharpley, Bitsika, & Efremidis, 1997; Smith, Oliver, & Innocenti, 2001) and parents of children with other developmental disabilities (Abbeduto et al., 2004; Dumas et al., 1991; McKinney & Peterson, 1987; Sanders & Morgan, 1997; Weiss, 2002). There is debate as to why this is the case. Research efforts have focused on the parents' well-being in relation to their child's symptomatology, resulting in mixed findings. Some studies have found the child's behavior problems to be associated with a parent's stress (Abbeduto et al., 2004; Hastings et al., 2005b; Tehee, Honan, & Hevey, 2009), while others have found a child's regulatory problems or deficits and delays in a child's social skills to have stronger associations (Davis & Carter, 2008). Another dimension to this issue is that there are probably gender differences in what a mother will find distressing compared to a father (Davis & Carter, 2008; Hastings, 2003; Hastings et al., 2005a). There is also evidence that mothers of children with ASDs experience higher levels of both depressive symptoms and stress than do fathers (Davis & Carter, 2008; Tehee et al., 2009).

While research has shown that parents of children with ASDs are at risk for mental illness, there are many families that have adjusted relatively well to raising a child with a disorder on the spectrum. How do these parents cope, and what kind of coping is the most beneficial when facing such a family crisis? Coping is defined as a reaction to a stressor. Both general and family-oriented theories about stress and coping (e.g., Lazarus, 1984, McCubbin & Patterson, 1983) state that developing individual and/or family strategies in response to stress is one of the requirements for successful adaptation (Hastings et al., 2005a). There is some debate about how coping impacts parental emotional well-being, with three different models being suggested and investigated (Aldwin & Revenson, 1987; Folkman & Lazarus, 1988). One idea is that coping directly affects emotional well-being, independent of how powerful a stressor is perceived to be or its effect (Pottie & Ingram, 2008). The stress-buffering model suggests that coping is mainly a moderator of emotional well-being and stressors (Pottie & Ingram, 2008). Lastly, coping is proposed to act as a mediator, with a stressor influencing coping responses, which in turn influence emotional well-being (Pottie & Ingram, 2008). The direct effects model has generally been supported more than the other two models, with past research investigating coping with parents of children with disabilities (Pottie & Ingram, 2008).

There is some consensus that problem-based coping strategies are correlated with greater well-being, while the inverse relationship has been found for the use of emotion-based coping (Glidden, Billings, & Jobe, 2006; Hastings et al., 2005a; Smith, Seltzer, Tager-Flusberg, Greenberg, & Carter, 2008). Some agreement also exists in the literature that parents of older children (10-21 year olds) with ASDs tend to rely more on emotion-based coping (Gray, 2002; Smith et al., 2008). More specific operationalizations of coping strategies other than the labels of *problem-based coping* ("aimed at solving the problem or doing something to change the source of stress") and *emotion-based coping* ("aimed at reducing or managing feelings of distress associated with the stressor") (Benson, 2009) are difficult to find. Sivberg (2002) found differences in the coping strategies implemented by parents of children with ASDs and the strategies used by parents with non-ASD children. The latter group was more likely to use social support, problem solving, and self-control, whereas the parents of children with ASDs were likely to use distancing and escape to cope (Sivberg, 2002). Hastings et al. (2005a) looked at coping strategies in both parents. The use of active avoidance coping was related to more stress and mental health problems, with mothers reporting they used this type of coping more frequently. Religious/denial coping was also found not to be beneficial to either parent's mental well-being. Most of the research in this area fails to provide a good, full picture for several reasons. One is that most of the researchers have only looked at maternal coping. Another issue is that researchers have usually classified coping in a dichotomous fashion as either *problem-based coping* or *emotion-based coping*, which oversimplifies the coping methods (Benson, 2009) and does not help to provide more detailed information. Specifically in regards to developmental disabilities researchers, the use of the term ‘coping’ has been generic and there is little standardization in its measurement (Glidden et al., 2006).

Social support has been found to help parents cope with the challenges of raising a child with ASD. In one study, social support from sources such as family, school, respite services, and other parents of children with ASD greatly helped in relieving stress (Tehee et al., 2009). The informal sources of support may be of particular importance (Hastings & Johnson, 2001). Altiere and von Kluge (2009) found differences in the levels of social support viewed by parents, with mothers feeling great amounts of social support and fathers feeling less support, some even reporting lost friendships due to their child’s disability. Heiman and Berger (2008) found within their sample that the parents of children with Asperger Syndrome scored low on all measures of support, interpreting this as a greater need for social support or the deterioration of their social connections due to the demands of raising a child with that disability. While this lack of social support can negatively impact parents, it can also extend its impact to other family members. Rivers and Stoneman (2003) showed that, in family systems where there was high marital stress, the families that used informal sources of social support such as friends or neighbors also had better quality of sibling relationship between the child with autism and their neurotypical siblings.

The purpose of the present study was to investigate how parental well-being relates to several of the factors that have been previously studied in this area of research. The factors I selected were coping, social isolation, and support. I chose depression and anxiety to be indicators of emotional well-being because most of the past research done with this population has used them as their indicators. Coping strategies are important for any family facing a crisis

(McCubbin & Patterson, 1983). Seeking social support has specifically been shown to be an important strategy with this population (Altiere & von Kluge, 2009; Tehee et al., 2009). Both mothers and fathers were studied in order to control for gender differences and to get a better understanding of the overall effects on parental, emotional well-being.

A great deal of the research with this population has only studied emotional well-being with mothers of children with ASDs. The study contributes to the literature by adding to the knowledge of how the emotional well-being of both mothers *and* fathers are affected differently by the challenges of raising a child with an ASD. This study combined factors that have often been studied separately in relation to the emotional well-being of parents of children with ASDs. To be able to study these factors simultaneously with one sample helps to clarify the complexities of the interactions among them.

The current study investigated the following hypotheses:

Emotional well-being

Mothers would report higher levels of stress and depressive symptoms than fathers.

Parents whose child had been diagnosed within the past year or who had an older child with an ASD would report high levels of stress and depressive symptoms.

Coping

Parents' use of problem-based coping strategies would be negatively correlated with levels of stress and depressive symptoms. Parents of older children (10 years and up) with ASDs would use more emotion-based coping strategies than parents of younger children.

Social isolation and support

Parents would rely more on informal than formal sources of support. Mothers would report having a greater number and more satisfying sources of support than would fathers. Fathers would feel more socially isolated than mothers.

Method

Participants

The 221 adult participants were individuals who reported being parents or guardians (hereafter referred to as “parents”) of children with ASDs. Their children had to be school-aged (4 to 18 years old) and have been (according to parent report) officially diagnosed with Autistic Disorder, Asperger’s Syndrome, or PDD-NOS by a psychological, medical, or educational professional. Their children had to have no reported physical handicaps and they were also not reported to have a genetic or chromosomal disorder (e.g., Fragile X Syndrome, Down Syndrome, Rett’s Disorder, Tuberous Sclerosis) or Childhood Disintegrative Disorder. However, not all participants were included in every analysis. This was due to some of the parents not providing answers that could be coded for all sections of the questionnaire. A few additional participants started the questionnaire, but exited the site, and later on restarted and completed the survey. Their first attempts were not included since they were only duplications of what they reported in their completed questionnaires.

The majority of the analyzed sample was female, Caucasian, had at least some college education, and was married or living with a partner. Most were employed, especially full-time, and had an annual household income of $50,000 or above. Nearly all lived with their child full-time. About half of their children had received the diagnosis of Autistic Disorder, while the other half had the diagnosis of either Asperger Syndrome or PDD-NOS. Their children were also primarily Caucasian. The majority of them attended public schools, where they were in regular classes, special education classes, or some combination of the two. There were 7 couples in the sample.

Materials

Sociodemographics

A ***Demographic Questionnaire*** requested information about both the parent and the child (location, gender, age, and ethnicity), parent information (relationship to child, marital status, employment, and highest level of education), child information (legal initials, diagnosis, placement in school, intervention history, and current interventions), and household information (income and other financial supports). (See Appendix A.)

Emotional well-being

The ***Short Form of the Profile of Mood States*** (POM-SF; Shacham, 1983) is a shorter version of the Profile of Mood States (POM) developed by McNair, Lorr, and Doppleman (1971). It has 37 items in total and is made up of six scales: Tension-Anxiety, Depression-Dejection, Anger-Hostility, Vigor-Activity, Fatigue-Inertia, and Confusion-Bewilderment. The POM-SF uses a 5-point Likert scale ranging from 0 (“Not at all”) to 4 (“Extremely”) to rate lists of adjectives associated with different moods. It has high internal consistency (α= 0.76-0.95), with some of the scales showing higher internal consistency than the same ones on the POM (Curran, Andrykowski, & Studts, 1995; Shacham, 1983). The correlation coefficients between the POM and the POM-SF have been found to be above 0.95 on all the scales, making it an excellent alternative to the lengthy original (Curran et al., 1995; Shacham, 1983). (See Appendix B).

The ***Family Stress and Coping Questionnaire*** (FSCQ-A; Tehee, Honan, & Hevey, 2009) was adapted from the Family Stress and Coping Interview (FSCI; Minnes & Nachsen, 2003). It assesses parents' level of perceived stress in 19 areas of their lives, including those affected with raising a child with ASDs (e.g., acquiring respite care, explaining their child's disorder to friends/ family/ community). It consists of 26 self-report items using a 4-point Likert scale ranging from 0 ("Being Not Stressful") to 3 ("Extremely Stressful"), as well as an open-ended question asking the parents to list their top 3 sources of stress. Good internal consistency was found in the population of Tehee et al.'s (2008) study ($\alpha = 0.72$). (See Appendix C).

Coping

The ***Brief COPE*** (Carver, 1997) is a self-report questionnaire used to assess a number of different coping behaviors and thoughts a person may have in response to a specific situation. 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. After reading a situationally-specific scenario, 28 coping behaviors and thoughts (2 items for each subscale) are rated on frequency of use by the participant with a scale of 1 ("I haven't been doing this at all") to 4 ("I've been doing this a lot"). Internal reliabilities for the 14 subscales range from α= 0.57-0.90 (Carver, 1997), and similar results have been found with a population of parents of children with ASDs (α= 0.54-0.93) (Benson, 2009). The wording was modified for the present study in order to fit the population and the challenges they face. Based on the definitions of problem-based and emotion-based coping, items 2,7,10, 14, 23, and 25 were classified as problem-based coping and the rest of the items fell into emotion-based coping. (See Appendix D.)

Social isolation and support

The ***Social Isolation subscale from the Parent Domain of the Parenting Stress Index*** (PSI; Abidin, 1986) consists of 6 self-report items. Other than assessing the parent's social isolation, it also looks at the social support available for the individual as a parent. The subscale has internal reliability (α= 0.73) (Hauenstein, Scarr, & Abidin, 1986). Participants are asked to rank each statement on a 5-point likert scale, with 1 being "Strongly Agree" and 5 being "Strongly Disagree." (See Appendix E.)

The ***Support Questionnaire*** (SQ), developed by Tehee et al. (2009), identifies how helpful an informal or formal source of support is to a parent of a child with an ASD. There was a total of 22 items (11 formal sources and 11 informal sources) and the open-ended question to list the three greatest sources of support. For informal sources, participants could choose to rate each source as "Poor," "Satisfactory," "Excellent," or "Not available." The responses to rate each formal source were "Poor," "Satisfactory," "Excellent," "Not available and needed," or "Not available and not needed." The measure also has good internal consistency (α= 0.77) (Tehee et al., 2009). (See Appendix F.)

Procedure

Participants were recruited through the Center for Autism and Related Disabilities (CARD) listserv and emailing lists of parent support groups across the United States. They were contacted with an email that described the study, eligibility to participate, procedure, and potential benefits and risks. The link to complete the survey was on the bottom. The email encouraged participants to forward the email to others who might be eligible to participate in order to create a 'snow ball' effect. Recruitment was also carried out by word of mouth at events scheduled by parent support organizations, such as family picnics and conferences. Parents and guardians were informed that the email was going to be sent out and encouraged to look at it.

Results

The internal consistency for all the measures was satisfactory, with alpha levels ranging from α= 0.60-0.93. The Brief COPE and SQ were divided into further "subscales" for the purpose of the analyses, and their internal consistency was also assessed. The Brief COPE (α= 0.81) was divided into problem-based and emotion-based coping (α= 0.79 and α=0.75, respectively). The SQ (α= 0.84) was divided into formal support (α=0.80) and informal support (α=0.80). Further information about the measures, including their means and standard deviations, can be found in Table 1.

Table 1: Scale Statistics for the Present Sample

Scale	Cronbach's alpha	Mean	Std. Deviation
Brief COPE (Combined)	.807	61.10	9.866
Brief COPE (Emotion-based)	.754	43.44	7.633
Brief COPE (Problem-based)	.791	17.66	3.859
FSCQ-A	.603	89.13	97.042
POM-SF Depression-Dejection	.932	9.06	7.658
POM-SF Tension-Anxiety	.886	9.21	5.552
PSI- Social Isolation	.743	14.9608	7.17126
SQ	.836	13.8153	4.69110
SQ- Formal	.798	6.6847	2.79295
SQ- Informal	.801	7.1306	2.91448

Emotional well-being

In order to test for gender differences in the levels of depressive symptoms, a t-test was conducted using the POMS-SF Depression-Dejection scores. Another t-test was calculated using the POMS-SF Tension-Anxiety scores in order to test for gender difference in the levels of stress symptoms. For both of the analyses, information from 211 parents was used (171 females, 40 males). No significant differences were found between the means of the mothers and fathers, either in levels of depressive symptoms (*M*s= 1.15 and 1.08, respectively) (*t*= -0.394, *df*= 209) or stress symptoms (*M*s = 1.58 and 1.43, respectively) (*t*= -0.876, *df*= 209).

Two t-tests were planned to examine whether a child's time of diagnosis (within the past year vs. earlier) predicted the parents' levels of stress and depressive symptoms, one t-test using POMS-SF Tension-Anxiety scores and the other using POMS-SF Depression-Dejection scores. However, very few of the participants had children who were diagnosed within the past year. In a few cases, it was impossible to determine an accurate time of diagnosis given the information parents provided. Thus, these analyses could not be done.

In order to examine if parents who had older children would report higher levels of stress and depressive symptoms, a t-test was performed using the age of the child (younger than 10 years vs. older) as the independent variable and the parent stress level (POMS-SF Tension-Anxiety scores) as the dependent variable. For this analysis, the information was provided from 198 parents. Group sizes were fairly equivalent, with 91 parents having younger children and 107 parents having children who were 10 years or older. There were no significant differences between the two group means (*M*s = 1.66, and 1.49, respectively) (*t*= 1.229, *df*= 196). Another t-test was run with the same two groups, but with level of depressive symptoms (POMS-SF

Depression-Dejection scores) as the dependent variable. Again, there were no significant differences between the two group means (*M*s = 1.26, and 1.03, respectively) (t= 1.751, df= 196).

Coping

In order to find out whether degree of use of problem-based coping was negatively correlated to stress levels, a correlation was done with the problem-based coping scores (the sum of responses to items 2,7,10, 14, 23, and 25) of 154 participants and their scores from the POMS-SF Tension-Anxiety subscale. To see whether problem-based coping was negatively correlated with levels of depressive symptoms, their problem-based coping scores (the sum of responses to items 2,7,10, 14, 23, and 25) and their scores from the POMS-SF Depression-Dejection subscale were used in a correlation. No significant relationship was found with either correlation.

Two correlations were run to see whether emotion-based coping was positively correlated with levels of stress and depressive symptoms. Emotion-based coping scores (the sum of items 1, 3, 4, 5, 6, 8, 9, 10, 11, 12, 13, 15, 16, 17, 18, 19, 20, 21, 22, 24, 26, 27, and 28) of the same 154 individuals, were correlated with POMS-SF Tension-Anxiety scores and POMS-SF Depression-Dejection scores, respectively. Both of these correlations were significant, with r= 0.253 for Tension-Anxiety and r= 0.219 for Depression-Dejection, $\underline{p} < .01$. In other words, the greater parents' use of emotional-based coping was, the greater their reported feelings of depression and anxiety.

Further exploratory analyses were carried out on sub-scales of the Brief COPE as an alternative to a dichotomous approach of looking at coping. Information from the same 153 to 154 parents was used in a series of correlations between the scores of each subscale of the Brief COPE (self-distraction, active coping, denial, substance abuse, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion, and self-blame) and the scores for Tension-Anxiety and Depression-Dejection. Results of these analyses can be seen in Table 2. As is apparent, greater use of self-distraction coping, denial coping, substance abuse coping, behavioral disengagement coping, venting coping, and self-blame coping was associated with increased feelings of stress and depression. Greater use of emotional support coping, positive reframing coping, and religion coping was associated with decreased feelings of depression.

Table 2: Coping Subscales Correlations		Mean of Tension POMS	Mean of POMS Depression
Mean of Self-Distraction Coping	Pearson Correlation	.226**	.220**
	Sig. (2-tailed)	.001	.006
	N	154	154
Mean of Active Coping	Pearson Correlation	.082	-.036
	Sig. (2-tailed)	.312	.654
	N	154	154
Mean of Denial Coping	Pearson Correlation	.257**	.355**
	Sig. (2-tailed)	.001	.000
	N	154	154
Mean of Substance Abuse Coping	Pearson Correlation	.207*	.282**
	Sig. (2-tailed)	.010	.000
	N	153	153
Mean of Emotional Support Coping	Pearson Correlation	-.105	-.204**
	Sig. (2-tailed)	.195	.011
	N	154	154
Mean of Instrumental Support Coping	Pearson Correlation	.108	-.109
	Sig. (2-tailed)	.182	.179
	N	154	154
Mean of Behavioral Disengagement Coping	Pearson Correlation	.270**	.441**
	Sig. (2-tailed)	.001	.000
	N	154	154
Mean of Venting Coping	Pearson Correlation	.260**	.292**
	Sig. (2-tailed)	.001	.000
	N	154	154
Mean of Positive Reframing Coping	Pearson Correlation	-.105	-.215**
	Sig. (2-tailed)	.195	.008

	N	154	154
Mean of Planning Coping	Pearson Correlation	.055	.006
	Sig. (2-tailed)	.500	.937
	N	154	154
Mean of Humor Coping	Pearson Correlation	.036	.023
	Sig. (2-tailed)	.655	.779
	N	154	154
Mean of Acceptance Coping	Pearson Correlation	-.026	-.137
	Sig. (2-tailed)	.754	.090
	N	154	154
Mean of Religion Coping	Pearson Correlation	-.093	-.169*
	Sig. (2-tailed)	.252	.037
	N	153	153
Mean of Self-Blame Coping	Pearson Correlation	.463**	.537**
	Sig. (2-tailed)	.000	.000
	N	153	153

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

A t-test was performed using the age of the child (younger than 10 years vs. older) as the independent variable and the parent's emotion-based coping scores (the sum of responses to items 1, 3, 4, 5, 6, 8, 9, 10, 11, 12, 13, 15, 16, 17, 18, 19, 20, 21, 22, 24, 26, 27, and 28) as the dependent variable. Data for the analysis came from 201 parents (93 parents of younger children and 108 parents of older children). No significant differences were found between the means of parents of younger children (*M*= 1.97) and parents of older children (*M*= 1.98) (*t*= -.290, *df*= 199), so this prediction was not supported.

Social support and isolation

In order to see whether parents rely more on informal than formal sources of support, a t-test was conducted using the sum of the number of informal sources and the sum of the number of formal sources from the SQ. The analysis was conducted using the information of 213 participants. Participants endorsed more sources of formal support (*M*= 6.93) (*t*= 40.05, *df*= 212) than informal sources of support (*M*= 7.40) (*t*= 41.22, *df*= 212), thus supporting this prediction.

To find out whether mothers have a greater number of sources of support than fathers, an independent t-test was performed with gender as the independent variable and the total number of different sources from the SQ as the dependent variable. No significant gender differences were found in terms of total number of sources of support. However, there was a significant gender difference in number of sources of formal support used, (fathers' *M*= 7.35 and mothers' *M*= 6.83) (*t*= 1.169, *df*= 211).

Gender differences in the level of satisfaction with sources of social support were assessed using a t-test on the sum of the levels of satisfaction from the SQ. No significant differences were found between the means for fathers and mothers for formal (*M*s= 1.87 and 1.90, respectively) (*t*= -0.381, *df*= 211) or informal support (*M*s = 2.01 and 1.98, respectively) (*t*= 0.380 *df*= 211).

Gender differences in the perceived level of social isolation were tested with a t-test on the scores from the Social Isolation subscale from the PSI. Again, no significant differences were found between the means for fathers and mothers (*M*s = 2.55 and 2.48, respectively) (*t*= 0.367, *df*= 207).

A few more analyses were conducted in order to explore formal and informal support use in relation to feelings of stress and depression. Two correlations were carried out with the average scores for formal support satisfaction of 211 participants, one using their POMS-SF Depression-Dejection scores and the other using POMS-SF Tension-Anxiety scores. A significant relationship was not found between level of satisfaction with formal support and feelings of stress. However, a significant relationship was found with feelings of depression (*r* = -.220, *p* < .01). Another set of correlations were carried out with the average scores for informal support satisfaction of the same 211 participants. One correlation used their POMS-SF Depression-Dejection scores and the other used their POMS-SF Tension-Anxiety scores. Significant relationships were found with both of these analyses (Depression-Dejection *r* = -.251 and Tension-Anxiety *r* = -.316, *p* < .01) .

Additional Analyses

While no predictions were made regarding scores from the Family Stress and Coping Questionnaire (FSCQ-A), analyses were carried out in order to get more detailed information on stress and coping in relation to being a caregiver to a child with an ASD. A t-test was carried out to investigate possible gender differences using the mean scores on the FSCQ-A of 214 parents (174 mothers, 40 fathers). A significant difference was found to between the scores of the mothers (*M*= 2.82) and fathers (*M*= 1.66) (*t*= -2.225, *df*= 212).

In order to see what specific situations were related to feelings of stress and depression, a series of correlations were carried out with the mean scores of each of the 25 questions of the FSCQ-A and the scores for Tension-Anxiety and Depression-Dejection. Significant relationships were found for 20 of the 25 situations listed on the FSCQ-A. Statistical results of these significant correlations can be found in Table 3.

Table 3: Signifcant FSCQ-A Correlations		Mean of Tension POMS	Mean of POMS Depression
Diagnosis of child as having ASD	Pearson Correlation	.166*	.187**
	Sig. (2-tailed)	.016	.006
	N	211	211
Possible causes of child’s disability	Pearson Correlation	.230**	.248**
	Sig. (2-tailed)	.001	.000
	N	210	210

Explaining child’s disability to family	Pearson Correlation	.358**	.326**
	Sig. (2-tailed)	.000	.000
	N	211	211
Explaining child’s disability to friends	Pearson Correlation	.364**	.323**
	Sig. (2-tailed)	.000	.000
	N	210	210
Explaining child’s disability to people in the community	Pearson Correlation	.407**	.343**
	Sig. (2-tailed)	.000	.000
	N	211	211
Interacting with family members	Pearson Correlation	.401**	.380**
	Sig. (2-tailed)	.000	.000
	N	209	209
Interacting with friends	Pearson Correlation	.332**	.333**
	Sig. (2-tailed)	.000	.000
	N	211	211
Interacting with people in the community	Pearson Correlation	.385**	.406**
	Sig. (2-tailed)	.000	.000
	N	208	208
Dealing with doctors or other health professionals regarding child	Pearson Correlation	.242**	.197**
	Sig. (2-tailed)	.000	.004
	N	209	209
Creating and/or finding opportunities for child to make friends/participate in activities	Pearson Correlation	.327**	.310**
	Sig. (2-tailed)	.000	.000
	N	209	209
Deciding the best level of integration for child	Pearson Correlation	.352**	.357**
	Sig. (2-tailed)	.000	.000
	N	209	209
Parents meeting own personal needs	Pearson Correlation	.459**	.467**
	Sig. (2-tailed)	.000	.000
	N	210	210
Parents maintaining satisfying personal friendships	Pearson Correlation	.356**	.371**
	Sig. (2-tailed)	.000	.000
	N	209	209
Dealing with child’s sexuality	Pearson Correlation	.233**	.284**
	Sig. (2-tailed)	.001	.000
	N	209	209
Thinking about	Pearson Correlation	.280**	.366**

present/future work placements or employment for child	Sig. (2-tailed)	.000	.000
	N	208	208
Thinking about present/future long-term accommodation for child	Pearson Correlation	.277**	.352**
	Sig. (2-tailed)	.000	.000
	N	211	211
Planning wills, trusts and/or guardianships for child	Pearson Correlation	.302**	.295**
	Sig. (2-tailed)	.000	.000
	N	209	209
Planning emotional and social support for child	Pearson Correlation	.382**	.403**
	Sig. (2-tailed)	.000	.000
	N	211	211
Planning assistance with care	Pearson Correlation	-.153*	-.204**
	Sig. (2-tailed)	.043	.007
	N	176	176
Attaining respite care	Pearson Correlation	-.164*	-.170*
	Sig. (2-tailed)	.041	.033
	N	156	156

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

Discussion

Results from this study support a number of previous findings relating to emotional well-being in parents of children with ASDs. These results provide evidence that there is a negative relationship between use of emotion-based coping and greater well-being (Glidden et al., 2006; Hastings et al., 2005a; Smith et al., 2008). The beneficial role of social support (Altiere & von Kluge, 2009; Hastings & Johnson, 2001; Tehee et al., 2009) was demonstrated in finding that its use was associated with lower feelings of tension/anxiety and depression in this population. In congruence with Hastings and Johnson (2001), informal sources of support were particularly important for this population, as evidenced by the parents' higher number of informal sources and greater satisfaction with them compared to formal sources.

Contrary to what was predicted and what has been found in the literature (Davis & Carter, 2008; Tehee et al., 2009), there were not many gender differences found within the sample studied. The absence of a gender difference was especially unusual in terms of the relationship between gender and feelings of stress and depression. This correlation is one that has been investigated the most in research looking at the emotional well-being of parents of children with ASDs. However, the equivalent results between mothers and fathers might be due to caregiving and involvement, not gender. This idea is supported by the differences found in the scores on FSCQ-A. The measure looks at stress and coping specifically related to providing care to a child with an ASD, in contrast with the Brief COPE or the POMS-SF Tension-Anxiety which provide more general assessments. Mothers traditionally have been more involved than fathers in the care of their children, especially on a daily basis. It is important to remember that the sample was recruited through parent support groups. These parents are more likely to be involved in the care and decisions involving their child than parents who are not affiliated with any support group. If both male and female members of these support groups play active roles in parenting their child, differences normally seen between mothers and fathers might not be replicated. It is necessary in future research to assess parental involvement in order to determine whether this is truly the case.

Due to the predominantly dichotomous way of studying coping, it is not really possible to compare the present findings to the rest of the literature with this population in terms of specific behaviors and cognitions. However, 10 of the 14 subscales on the Brief COPE displayed at least one significant relationship with emotional well-being, indicating that a clearer picture can be gathered. Future studies should aim to examine coping in more detail, as it would help to provide valuable information on what forms of coping should be encouraged for parents of children with ASDs.

The study had a few limitations. First, more mothers completed the survey than fathers. More accurate results could be acquired with a larger sample of fathers. Another challenge arose as a result of some questions being left blank throughout the survey, leading to participant exclusion on some analyses. It may be beneficial to review the settings on the online questionnaire and set it to make all or a larger percentage of the questions necessary to complete. It is also uncertain if the sample was representative of the general population of parents with ASD due to the parents’ high likelihood of being associated with a support group. It is possible that the participants may have had better emotional well-being than the average parent of a child with an ASD. This possibility should be explored by using different recruiting methods in the future.

The findings highlight the importance of considering parents in ASD treatments. Across the thousands of different autism interventions that exist, the two factors that are emphasized again and again are intense levels of early intervention and making the intervention generalizable across settings. A trend is emerging for parents to become involved in these interventions to aid in generalizability and consistency. The recommended intensity level of early intervention is 20 to 30 hours a week (Dawson et al., 2010; Hallam, Rous, Grove, & LoBianco, 2009; Stahmer & Mandell, 2007), a great demand of parents’ time. Some researchers have found an increase in maternal stress when there was early intervention (Brinker, Seifer, & Sameroff, 1994). Even if the child is older than 3 years (the early intervention cutoff age), having various specialists in the home and requiring involvement could be stressful to a parent. Robbins, Dunlap, and Plienis (1991) found a strong relationship between the stress of the mother pre-intervention and the autistic child’s progress, suggesting that parental emotional well-being is an important factor to consider. From these findings, it is a clear conclusion that addressing parental stress and coping is important on a number of different levels. First, the emotional well-being of an individual has a large impact on their overall well-being; parents are not exceptions to this rule. Secondly, parents with healthy emotional well-being will adapt better to the challenges of raising a child with an ASD and be able to assist in their child’s interventions. Finally, parental stress may have direct or indirect affects on the child with an ASD. The emotional well-being of parents needs to be addressed in order to increase the desired benefits for children with ASD and their families.

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Appendix A: Demographic Questionnaire

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

1. What year were you born?
1 9 ___ ___

2. What is your gender?

- ○ Male
- ○ Female

3. Which racial group best describes you?

- ○ 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 Hawaiian 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. Are you currently employed?
- ○ Yes
- ○ No

6. Which state do you currently live in? : _____________

7. 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.

8. What is your relationship to your child?
- ○ Biological mother
- ○ Biological father
- ○ Adoptive mother
- ○ Adoptive father
- ○ Legal guardian—Specify________________

9. What is your child's date of birth? : ___ ___/___ ___/___ ___
Month Day Year

10. What are the initials of your child's legal name? For example, John-Patrick James Doe would be JPJD.

____

11. What is your child's gender?
- ○ Male
- ○ Female

12. Does your child live with you_____?

- ○ Full time
- ○ Part time
- ○ None of the time

13. Which racial group best describes your child? Please circle all that apply.
- ○ 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 Hawaiian or Pacific Islander

○ White or Caucasian
○ Other – Specify ____________________________
○ More than one race – Specify ____________________________

14. What diagnosis has your child received?
○ Autistic Disorder
○ Asperger Syndrome or Asperger's Disorder
○ Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)

15. Who diagnosed your child?
○ Physician/ Medical doctor
○ Psychologist
○ Educational professional- Specify___________
○ Other- Specify___________

16. How old was your child when he or she received a diagnosis: ___________

17. 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_______________________

18. What grade is your child currently in? : _______________

19. 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____

20. 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

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

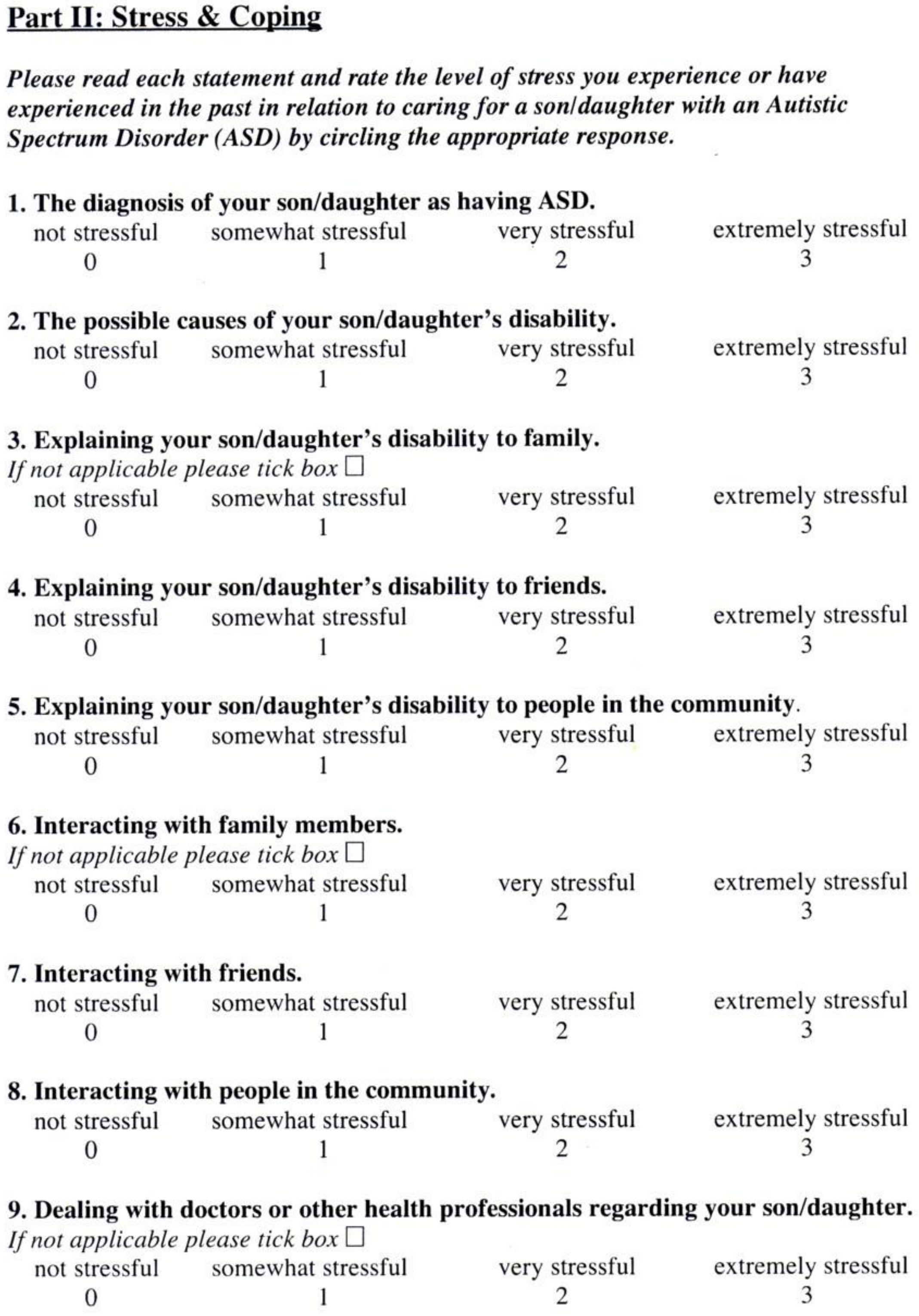
- ○ Private health insurance
- ○ Medicaid only
- ○ Medicaid Waiver
- ○ Other- Specify___________________

Appendix B: POMS- Short Form

Below is a list of words that describe feelings that people have. Please read each word carefully. Then select the number that best describes how you have been feeling generally.

	Not at all	A little	Moderately	Quite a bit	Extremely
1. Tense	0	1	2	3	4
2. Angry	0	1	2	3	4
3. Worn out	0	1	2	3	4
4. Unhappy	0	1	2	3	4
5. Lively	0	1	2	3	4
6. Confused	0	1	2	3	4
7. Peeved	0	1	2	3	4
8. Sad	0	1	2	3	4
9. Active	0	1	2	3	4
10. On edge	0	1	2	3	4
11. Grouchy	0	1	2	3	4
12. Blue	0	1	2	3	4
13. Energetic	0	1	2	3	4
14. Hopeless	0	1	2	3	4
15. Uneasy	0	1	2	3	4
16. Restless	0	1	2	3	4
17. Unable to concentrate	0	1	2	3	4
18. Fatigued	0	1	2	3	4
19. Annoyed	0	1	2	3	4
20. Discouraged	0	1	2	3	4
21. Resentful	0	1	2	3	4
22. Nervous	0	1	2	3	4
23. Miserable	0	1	2	3	4
24. Cheerful	0	1	2	3	4
25. Bitter	0	1	2	3	4
26. Exhausted	0	1	2	3	4
27. Anxious	0	1	2	3	4
28. Helpless	0	1	2	3	4
29. Weary	0	1	2	3	4
30. Bewildered	0	1	2	3	4
31. Furious	0	1	2	3	4
32. Full of pep	0	1	2	3	4
33. Worthless	0	1	2	3	4
34. Forgetful	0	1	2	3	4
35. Vigorous	0	1	2	3	4
36. Uncertain about things	0	1	2	3	4
37. Bushed	0	1	2	3	4

Appendix C: Family Stress and Coping Questionnaire (FSCQ-A)



Part II: Stress & Coping

Please read each statement and rate the level of stress you experience or have experienced in the past in relation to caring for a son/daughter with an Autistic Spectrum Disorder (ASD) by circling the appropriate response.

1. The diagnosis of your son/daughter as having ASD.

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

2. The possible causes of your son/daughter's disability.

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

3. Explaining your son/daughter's disability to family.

If not applicable please tick box ☐

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

4. Explaining your son/daughter's disability to friends.

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

5. Explaining your son/daughter's disability to people in the community.

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

6. Interacting with family members.

If not applicable please tick box ☐

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

7. Interacting with friends.

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

8. Interacting with people in the community.

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

9. Dealing with doctors or other health professionals regarding your son/daughter.

If not applicable please tick box ☐

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

10. Dealing with your son/daughter's therapy providers.

If not applicable please tick box ☐

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

11. Dealing with your son/daughter's teachers.

If not applicable please tick box ☐

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

12. Dealing with the education system.

If not applicable please tick box ☐

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

13. Creating and/or finding opportunities for your son/daughter to make friends and participate in activities.

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

14. Deciding the best level of integration for your son/daughter.

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

15. Meeting the needs of your other children.

If not applicable please tick box ☐

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

16. Meeting your own personal needs.

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

17. Meeting the needs of your spouse.

If not applicable please tick box ☐

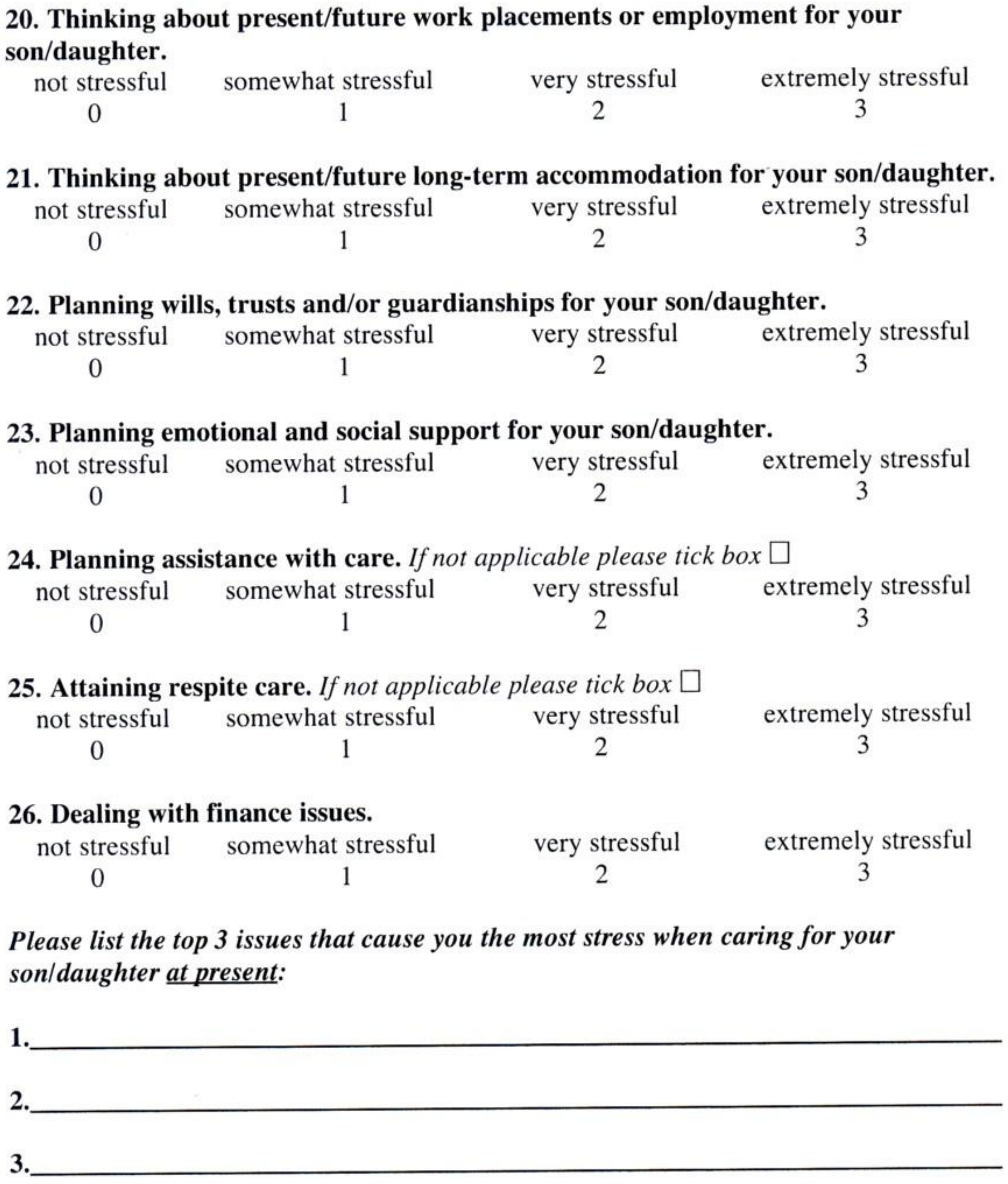
not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

18. Maintaining satisfying personal friendships.

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

19. Dealing with your son/daughter's sexuality.

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3



20. Thinking about present/future work placements or employment for your son/daughter.

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

21. Thinking about present/future long-term accommodation for your son/daughter.

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

22. Planning wills, trusts and/or guardianships for your son/daughter.

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

23. Planning emotional and social support for your son/daughter.

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

24. Planning assistance with care. *If not applicable please tick box* ☐

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

25. Attaining respite care. *If not applicable please tick box* ☐

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

26. Dealing with finance issues.

not stressful	somewhat stressful	very stressful	extremely stressful
0	1	2	3

Please list the top 3 issues that cause you the most stress when caring for your son/daughter <u>at present</u>:

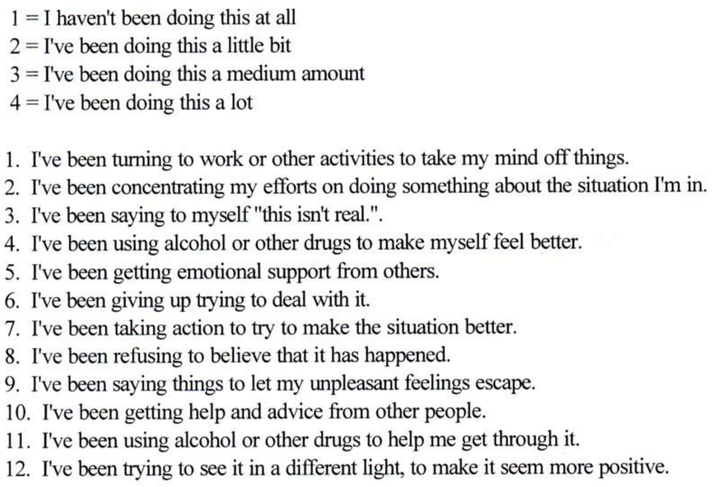
1.____

2.____

3.____

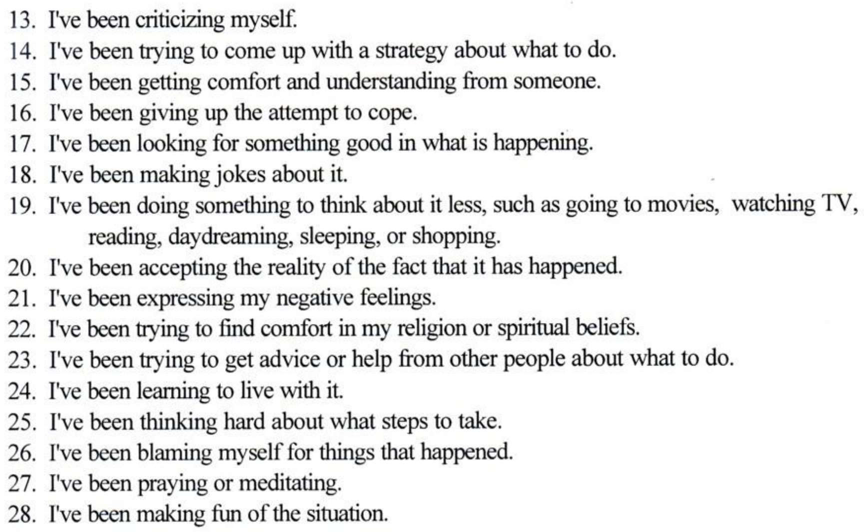
Appendix D: Brief COPE

These items deal with ways you’ve been coping with the challenges of raising a child with an autism spectrum disorder. There are many ways to try to deal with life’s challenges. These items ask what you’ve been doing to cope with this challenge. Obviously, different people deal with things in different ways, but I’m interested in how you’ve tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you’ve been doing what the item says. How much or how frequently. Don’t answer on the basis of whether it seems to be working or not—just whether or not you’re doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.



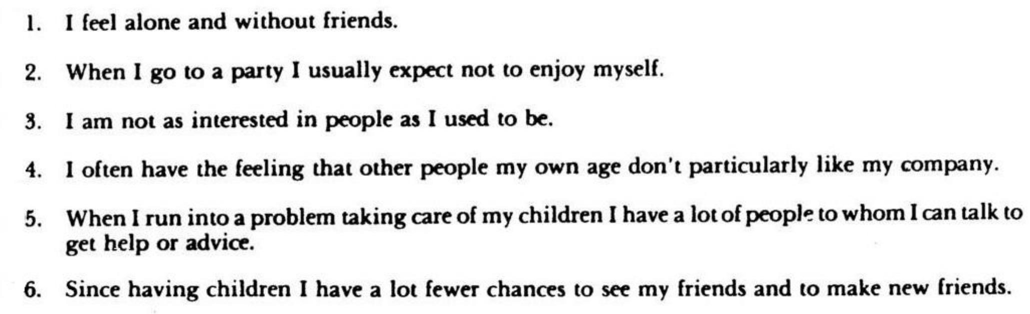
1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

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 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 E: PSI-Social Isolation Subscale



1. I feel alone and without friends.
2. When I go to a party I usually expect not to enjoy myself.
3. I am not as interested in people as I used to be.
4. I often have the feeling that other people my own age don't particularly like my company.
5. When I run into a problem taking care of my children I have a lot of people to whom I can talk to get help or advice.
6. Since having children I have a lot fewer chances to see my friends and to make new friends.

Appendix F: Support Questionnaire

In both Table A and Table B, please rate each potential source of support in terms of its helpfulness to you in caring for a son/daughter with ASD, by placing an ‘X in the appropriate column. In Table B, if service is not available (N/A) please respond in terms of whether this service is needed or not.

<u>Table A: Informal Support Network:</u>

	Poor	Satisfactory	Excellent	Not available
Spouse				
Children				
Female Friends				
Male Friends				
Maternal Grandparents				
Paternal Grandparents				
Mother’s Sister/s				
Father’s Sister/s				
Mother’s Brother/s				
Father’s Brother/s				
Religion/Faith				
Other (please specify)				

Table B: Formal Support Network

	Poor	Satisfactory	Excellent	Not available & needed	Not available & not needed
Support Groups					
Respite Care					
Financial Assistance					
Counseling Services					
Case manager					
ASD organizations					
School staff					
ASD Adult Services					
Primary Care Provider					
Specialized Physicians					
Therapy Providers					
Other (please specify)					