

A global model of stress in parents of individuals with autism spectrum disorders (ASD)

Pilar Pozo and Encarnación Sarriá*

UNED, Universidad Nacional de Educación a Distancia (España)

Título: Un modelo global de estrés en padres de personas con trastornos del espectro autista.

Resumen: Esta investigación tiene como objetivo el análisis del estrés en las madres y en los padres de personas con trastornos del espectro autista (TEA), con el fin de identificar las variables relevantes en la adaptación al estrés y las posibles diferencias de género. Proponemos un modelo multidimensional, basado en el modelo teórico Doble ABCX, en el que el resultado de estrés depende de cuatro factores interrelacionados: las características de la persona con TEA (severidad del trastorno y problemas de conducta), los apoyos sociales, la percepción de la situación (evaluada mediante el sentido de la coherencia) y las estrategias de afrontamiento. Cincuenta y nueve parejas (59 madres y 59 padres) con un hijo/a diagnosticado/a de TEA participaron en el estudio. Los datos fueron analizados utilizando *path* análisis a través del programa estadístico LISREL 8.80. Se obtuvieron dos modelos empíricos de estrés: uno para madres y otro para padres. En ambos modelos la severidad del trastorno y los problemas de conducta presentaron un efecto directo y positivo sobre el estrés. El sentido de la coherencia (SOC) y las estrategias de afrontamiento de evitación activa presentaron un papel mediador en los modelos. Los apoyos sociales resultaron relevantes sólo para las madres. Finalmente, se discuten las aportaciones de estos resultados para el trabajo de los profesionales con las familias.

Palabras clave: Trastornos del espectro autista; modelo doble ABCX; estrés parental; problemas de conducta; severidad del trastorno; sentido de la coherencia; apoyo social; estrategias de afrontamiento.

Abstract: This research sought to analyse stress among mothers and fathers of individuals with autism spectrum disorders (ASD) to determine the relevant variables for its explanation and the possible gender differences. To examine parents' stress, we propose a multidimensional model based on the Double ABCX theoretical model. We argue that the result of stress depends on the following four interrelated factors: the characteristics of the individual with ASD (the severity of the disorder and behaviour problems), the social supports, the parents' perception of the situation (evaluated by sense of coherence) and the coping strategies. Fifty-nine sets of parents (59 mothers and 59 fathers) of individuals diagnosed with ASD participated in the study. The data were analysed using a path analysis through the LISREL 8.80 program. We obtained two empirical models of stress: one model for mothers and one for fathers. In both models, the severity of the disorder and the behaviour problems had a direct and positive effect on stress. The sense of coherence (SOC) and active avoidance coping strategies had a mediating role in models. Social support was relevant only for mothers. Finally, the results offer some guidelines for professionals working with families.

Key words: Autism spectrum disorders; double ABCX model; parental stress; behaviour problems; severity of the disorder; sense of coherence; social support; coping strategies.

Introduction

The characteristics of Autism Spectrum Disorders (ASD) cause major disturbances in family dynamics and generate needs in all areas and contexts of development (Altieri, 2006; Baker, Blacher, & Olsson, 2005; Shu, 2009; Smith, Hong, Seltzer, Greenberg, Almeida, & Bishop, 2010). The specific characteristics of the individual with ASD, in particular the severity of the disorder and behaviour problems, are significant sources of parental stress.

Individuals with ASD present alterations in the following three areas of development: reciprocal social interaction, verbal and non-verbal communication, and flexibility in their selection of interests and behaviour. Several studies have found a positive relationship between the severity of children's impairment and the level of stress in their parents (Bebko, Konstantareas, & Springer, 1987; Bravo, 2006; Hastings & Johnson, 2001; Hoffman, Sweeney, & Lopez-Wagner, 2008; Kasari & Sigman, 1997; Konstantareas & Homatidis, 1989; Pozo, Sarriá, & Méndez, 2006; Szatmari, Archer, Fisman, & Streiner, 1994). In addition, behaviour problems in ASD (aggression, stereotyped behaviour, and self-injury) also have a strong positive association with parental stress (Baker, Blacher, Crnic, & Edelbrock, 2002; Bishop, Richler, Cain, & Lord, 2007; Estes et al., 2009; Her-

ring et al., 2006; Lecavalier, Leone, & Wiltz, 2006; Tomanik, Harris & Hawkins, 2004).

Comparative studies have systematically shown that parents of children with ASD present higher levels of stress than parents of children with intellectual disabilities (ID) or children with typical development (Baker-Ericzén, Brookman-Frazee, & Stahmer, 2005; Baker et al., 2003; Belchic, 1996; Cuxart, 1995; Konstantareas, 1991; Oizumi, 1997; Pisula, 2007). Seguí, Ortiz-Tallo and de Diego (2008) have evaluated the level of overload in a sample of Spanish caregivers of children with ASD and find that these caregivers are more overloaded than the general population.

Parental stress is considered a consequence of a complex set of significant and persistent challenges associated with care of the child (Pisula, 2011). In previous research on parents of individuals with ID, stress is commonly conceptualised as a relationship with the environment in which an individual perceives life's demands to be beyond his/her available resources and thus threatening to his/her well-being (Lazarus & Folkman, 1984).

Many parents however, have successfully managed the stress of raising a child with severe ASD and behaviour problems. The variables that affect stress management include social support, perception of the situation, and coping strategies.

Social support protects against stress and is negatively associated with stress in parents of individuals with autism (Bristol, 1984; Dyson, 1997; Konstantareas & Homatidis, 1989; Sanders & Morgan, 1997; Sharpley, Bitsika, & Efremidis, 1997). The parent's sense of coherence (SOC),

* Dirección para correspondencia [Correspondence address]:
Encarnación Sarriá Sánchez. Facultad de Psicología UNED. C/ Juan del Rosal, nº 10. 28040 Madrid (Spain). E-mail: esarria@psi.uned.es

that evaluates their perception of their situation, is significantly negatively associated with parental stress (Mak, Ho, & Law, 2007; Oelofsen & Richardson, 2006; Olsson & Hwang, 2002; Pozo et al., 2006). A strong SOC protects against stress. SOC is conceived as a personality characteristic that functions as a coping style, an enduring tendency to see one's life space as more or less orderly, predictable, and manageable (Antonovsky, 1987). Finally, previous research that examines coping strategies used by parents to manage daily situations demonstrates that parents who adopt positive reframing coping strategies report less stress than parents who adopt active avoidance coping strategies (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Hastings et al., 2005).

In summary, stress adaptation among parents of individuals with ASD is complex because multiple variables affect the outcome. The specific characteristics of the individual, the social support, the parents' sense of coherence and the parents' coping strategies are four such factors examined in this study. Most prior studies, however, have only implemented partial analyses of stress and have not accounted for the simultaneous effects and interrelationships of all of the variables involved in stress adaptation. To effectively examine the interrelationship between the variables and their influence on stress, it is necessary to adopt a multidimensional perspective.

The double ABCX model (McCubbin & Patterson, 1983) has proven to be an effective theoretical model for the global analysis of stress in mothers of individuals with ASD (Bristol, 1987; Pozo et al., 2006, Pozo, Sarriá, & Brioso, 2011) and for the analysis of adjustment in mothers of individuals with Asperger Syndrome (Pakenham, Sofronoff, & Samios, 2005).

A pioneering study using multidimensional analysis of maternal stress conducted by Bristol (1987) has found that the severity of the child's behavioural problems is positively associated with the parents' stress levels. Additionally, the strongest predictors of maternal stress are the mother's definition of the child's handicap and her level of informal social support. These results have been confirmed by Pozo et al. (2006) in a Spanish study of mothers of individuals with ASD. In addition, Pakenham et al. (2005) found that maternal adjustment (depression, anxiety, social adjustment and subjective health status) was related to the following variables: higher levels of qualitative social support; emotionally appropriate coping strategies, which include positive reinterpretation and the act of seeking social support; and lower levels of child behavioural problems, stress appraisals, and passive avoidance coping.

We note that these multidimensional studies have only examined mothers. The majority of studies on parental stress associated with raising a child with ASD have focused on mothers even though raising a child with autism presents significant challenges for fathers as well. One study shows that the level of stress in fathers of children with autism is

higher than the level of stress among fathers of normally developing children (Baker-Ericzén et al., 2005).

Likewise, there are few comparative studies that analyse the differences in parental stress between mothers of individuals with ASD and fathers of individuals with ASD. Some studies have found higher levels of stress in mothers than in fathers (Bristol, Gallagher, & Schopler, 1988; Gray & Holden, 1992; Hastings, 2003; Herring et al., 2006; Tehee, Honan, & Hevey, 2009; Trute, 1995), whereas others have not found gender differences (Benson, 2006; Cuxart, 1995; Dyson, 1997; Hastings et al., 2005). There is a lack of studies that analyse stress from a multidimensional perspective comparing maternal and paternal models and examining the commonalities and differences between them.

For this reason, our research has two objectives. The first objective is to perform a multidimensional analysis of stress to enhance the knowledge of different variables that make up the model and the relationships among them. The second objective is to examine how mothers and fathers experience parental stress differently by independently analysing mothers' and fathers' models of stress.

We propose a theoretical model based on the double ABCX model in which all the variables are interrelated. Figure 1 exhibits our hypotheses and identifies the directions and signs of the hypothesised relationships among the factors in the theoretical model for the analyses of parental stress. The application of the double ABCX model for the study of the psychological adaptation of parents of individuals with ASD (Pozo et al., 2006; 2011; Pozo, Sarriá, & Brioso, in press) suggests that the adaptation outcome (xX factor) depends on several factors. These factors include stressors or specific individual with ASD characteristics (aA factor), social support (bB factor), perception or definition of the situation (cC factor), and coping strategies (BC factor). The variables that constitute the factors in the model were derived from prior research on parents of individuals with ASD. The severity of the disorder and behaviour problems of individual with ASD represent the aA factor. Social support and sense of coherence (SOC) are associated with the bB and cC factors respectively. Two major types of coping strategies, positive and problem-focused coping and active avoidance coping, were introduced as variables of the BC factor to consider the type of coping strategy used rather than total scores of measuring coping.

The model postulates that the bB, cC and BC factors play mediating roles. In this sense, the variables based on the characteristics of individuals with ASD have two effects on stress: a) a direct effect on stress and b) an indirect effect on stress through social support, perception of the problem (evaluated by sense of coherence) and coping strategies (positive and problem-focused coping and active avoidance coping strategies). These three variables play a mediating role in the model of stress. Specifically, the severity of the disorder and behaviour problems is negatively associated with social support and SOC variables and positively associated with coping strategies. Two mediating variables (social

support and SOC) are negatively associated with stress, and coping strategies have a positive relation to stress. All three variables are associated with one another.

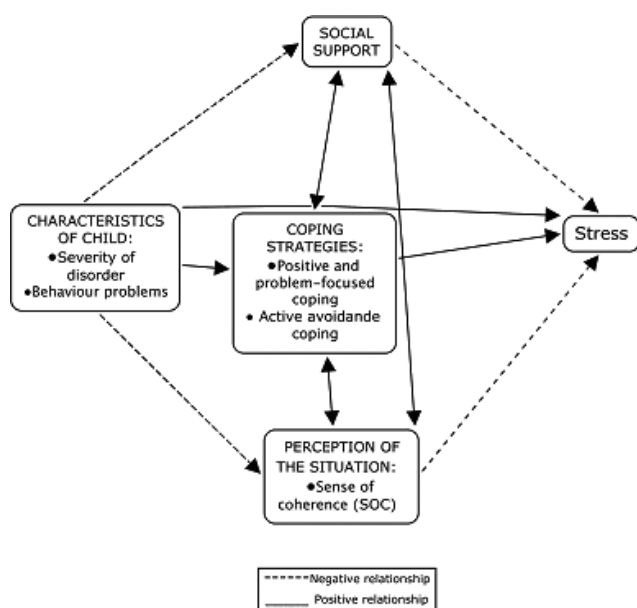


Figure 1. The theoretical model of stress in parents of individuals with autism spectrum disorders.

Method

Participants

Participants included 118 adults from Spain (59 mothers and 59 fathers comprising 59 couples). All of the couples had a son or a daughter diagnosed with ASD, lived together in the family home and spoke Spanish as their primary language. Most of the couples (96.6%) were married, and the rest (3.4 %) were stable unmarried couples. To homogenise the groups of mothers and fathers in terms of family context factors, the inclusion criterion for the sample was that both parents of the same family had completed the questionnaires.

Table 1 shows sample demographic characteristics. We observed that mothers and fathers were similar in age and level of education. We note that significant differences exist in employment levels ($\chi^2_{(2)} = 31.67, p < .01$), as 49.1% (29) of mothers were gainfully employed in comparison to 88.1% (52) of fathers. These data suggest that a greater proportion of mothers than fathers were involved in childcare as their main activity.

With regard to the characteristics of the individuals with ASD, the average age in the study was $M = 12.4$ years; 47 of the individuals with ASD were male, and 12 were female. The main category of ASD among participants was Autistic Disorder (43), followed by PDD-NOS (10), Rett's Syndrome (5), and Asperger's Syndrome (1). In relation to the severity of the disorder, the CARS test applied allows classi-

fy the individuals as not autistic (scores below 28), mild or moderately autistic (28–36) or severely autistic (scores above 36) (García-Villamizar & Muela, 1998; Mesibov, 1988). In our sample, all children (59) received scores above the autism cutoff (total score 28), 15.6% with mild-moderate autism (15) and 84.4% with severe autism (44).

Table 1. Demographic characteristic of parents, family and individuals with ASD.

Demographic information	% (n)	Mean (SD)
Mothers (n=59)		
Age (years) range 28-69		44.6 (7.9)
Level of Education		
Primary school	22.0 (13)	
Secondary school	35.6 (21)	
University	45.9 (25)	
Employed	49.1 (29)	
Father (n=59)		
Age (years) range 32-72		46.7 (9.1)
Level of Education		
Primary school	22.0 (13)	
Secondary school	37.3 (22)	
University	40.7 (24)	
Employed	88.1 (52)	
Family (n=59)		
Family composition		
3 members	23.7 (14)	
4 members	61.0 (36)	
5 members	19.3 (9)	
Individual with ASD (n=59)		
Age (years) range 4-38		12.4 (7.9)
Gender		
Male	79.7 (47)	
Type of ASD		
Autistic Disorder	72.9 (43)	
Asperger's Syndrome	1.7 (1)	
Rett's Syndrome	8.5 (5)	
PDD-NOS	16.9 (10)	
Severity of disorder		
Moderate	15.6 (15)	
Severe	84.4 (44)	
Education centre		
Ordinary school	25.4 (15)	
Special education school	12.2 (6)	
Autism-specific school	55.9 (33)	
Day centre	8.5 (5)	

Note. SD = Standard Deviation; ASD = Autism Spectrum Disorders; PDD-NOS = Pervasive Developmental Disorder-Not Otherwise Specified

Procedure

The heads of schools were initially contacted through the Professional Association of Autism in Spain (AETAPI) and informed of the aims of the research. Parents received a letter inviting them to participate in the study. We reported in the letter that the data obtained would be treated confidentially and used only for this research. We also informed parents that their participation was voluntary and they could leave the research at the time they so choose. Parents participated by completing a series of questionnaires distributed

via school or by mail, depending on the parents' preference. Further instructions were included with the questionnaires and stated that the questionnaires should be completed individually without consultation or discussion with the spouse.

A total of 161 parents (96 mothers and 65 fathers) completed the questionnaires. To standardise the groups of mothers and fathers in family context factors, the inclusion criterion for the final sample was that both parents of the same family had completed the questionnaires. In the end, 118 parents (59 mother-father couples from two-parent families) were included as participants.

Measures

Demographic information from parents, individuals with ASD and families was obtained through a brief questionnaire designed specifically for this research. A battery of six questionnaires was used to evaluate the variables that make up the stress model. One of these questionnaires (the *Childhood Autism Rating Scale*) was completed by the professionals, and the mothers and fathers completed the other five questionnaires individually. Some questionnaires were previously adapted for Spanish by other authors (*Childhood Autism Rating Scale* and Brief COPE). We translated the following measures into Spanish: the *Behaviour Problems Inventory*, the *Checklist of Support for Parents of the Handicapped*, the *Sense of Coherence Questionnaire*, and the *Parental Stress Index Short Form*. We adopted the back-translation technique to ensure translation accuracy. Two bilingual experts were invited to translate the Spanish versions back to English to correct differences between the two versions.

The *Childhood Autism Rating Scale* (CARS; Schopler, Reichler, & Reisner, 1988; adapted for Spanish by Garcia-Villamisar & Polaino-Llorente, 1992) was used to measure the severity of the disorder. The CARS is a 15-item behaviour scale, which evaluates behaviours that, in general, are affected by autism. Each item is scored from 1 (behaviour appropriate for age level) to 4 (severe deviance with respect to normal behaviour for age level). All items are added together into a total score, which was used in the present study to evaluate the severity of the disorder. The internal consistency of the original scale is high, with an alpha reliability coefficient of .94 and interrater reliability of .71. The Spanish adaptation of the CARS has both good internal consistency ($\alpha = .98$) and concurrent validity (Kappa coefficient = .78). The current study also exhibited good reliability, with a Cronbach's alpha of .91.

The *Behaviour Problems Inventory* (BPI; Rojahn, Matson, Lott, Svensen, & Smalls, 2001) was translated into Spanish for this study. The BPI was used to assess the behaviour problems of individuals with ASD. A 52-item scale, the BPI, also has three sub-scales: self-injurious, stereotyped and aggressive/destructive behaviour. Each item is scored on a 4-point severity scale ranging from 0 (no problem) to 3 (a severe problem). The reliability in the original scale is high, with a Cronbach's alpha of .83 for the total scale. The BPI

has been found to be a reliable and valid behaviour rating instrument for behaviour problems in individuals with mental retardation and developmental disabilities (Rojahn et al., 2001). The internal consistency of the total scale in the present study was also high, with $\alpha = .89$.

The *Checklist of Supports for Parents of the Handicapped* (CSPH; Bristol, 1979) was translated into Spanish and used to evaluate the useful social support that is available to parents caring for an individual with a disability. It is a 23-item rating scale using a 5-point item scale ranging from 0 (nothing useful) to 4 (very useful). The total score was used in this study and was obtained by summing all items. There was no information regarding the internal consistency of the original scale; in the present study, the reliability, based on Cronbach's alpha, was .82.

The *Sense of Coherence Questionnaire* (SOC; Antonovsky, 1987) was translated into Spanish and used to assess the sense of coherence (SOC). The questionnaire measures the extent to which individuals find life to be comprehensible (the ability to understand life events and situations as clear, ordered and structured), manageable (the sense that life is under control and demands can be managed) and meaningful (the perception that life situations and challenges are worthwhile). This is a 29-item scale, which is rated by a 7-point item scale, with higher scores indicating a stronger SOC. Antonovsky (1993) demonstrates good test-retest reliability and criterion validity. The Cronbach's alpha for the present sample was .90.

The *Brief Coping Orientation of Problems Experienced* (Brief-COPE; Carver, 1997; adapted to Spanish by Crespo & Cruzado, 1997) was used to obtain information on coping strategies used by parents raising an individual with ASD. It has 14 two-item subscales. Each item is rated in terms of how often the responder utilises a particular coping strategy as measured on a 4-point scale in which 0 represents "I have not been doing this at all" and 3 represents "I've been doing this a lot".

To reduce the number of strategies, we performed a principal component factor analysis following the methodology used by Hastings, Kovshoff, Brown et al. (2005). The results showed that two factors explained 28% of the variance; the two factors included items from the original Brief-COPE sub-scales. Factor 1, which is named "positive and problem-focused coping strategies", includes items for active coping, planning, seeking instrumental and emotional social support, positive reframing, and humour. Factor 2, which is named "active avoidance coping strategies", includes seven items from the sub-scales for denial, behaviour disengagement, distraction, and self-blame. Only the scores for these two factors were used in the current study. Reliability was good for the total scale ($\alpha = .76$), positive and problem-focused coping strategies ($\alpha = .79$), and active avoidance coping strategies ($\alpha = .71$).

The *Parental Stress Index Short Form* (PSI-SF; Abidin, 1995). This scale was translated into Spanish and used to evaluate the parental stress. This form is a 36-item self-report ques-

tionnaire. Response options range from 1 (totally disagree) to 5 (totally agree). The total score was obtained by summing all items; a score above 90 points indicates a clinically significant level of stress. Total stress score involves the following three categories: a) the parental domain (reflects the stress arising from the parent's perceptions of themselves and their functioning as a parent); b) the child characteristics domain (reflects the stress experienced as a result of the parent's perceptions of the child's characteristics and the demands made upon them by the child); and c) the parent-child interaction domain (reflects the stress caused by the perception of dysfunctional interaction with the child). The total stress score was used as the main dependent variable in the present research. The PSI-SF has very strong reliability and validity data, and the total stress score was also reliable in the present sample (Cronbach's $\alpha = .88$).

Data analysis

Pearson's correlations were used to explore bivariate associations between all of the variables that operationalise the double ABCX model factors in this study. Correlations were calculated using the SPSS 15 program, separately for mothers and fathers. Path analysis was carried out using the LISREL 8.80 program to form a multidimensional analysis of stress. Data for mothers and fathers were analysed separately and all of the variables were introduced in each model. Finally, a comparative analysis of mean differences between

mothers and fathers in the variables was performed using the SPSS 15 program. The G* Power 3.1 program (Faul, Erdfelder, Lang, & Buchner, 2007) was used for the post hoc power analysis and to calculate the effect size.

Results

We carried out Pearson's correlations to explore bivariate associations between all of the variables that operationalise the model factors in this study. Correlations were calculated separately for mothers and fathers and the results are shown in Table 2. The data show that for both samples the severity of disorder, behaviour problems, and active avoidance coping strategies are positively associated with the adaptation variable (stress), and SOC is negatively associated with stress. Social support is significantly correlated with stress only in the case of mothers (negatively associated). For both samples the two characteristics of the individual with ASD variables (the severity of the disorder and behaviour problems) are positively associated. The behaviour problems variable is positively correlated with active avoidance coping strategies, and SOC is negatively associated with behaviour problems and active avoidance coping strategies. In the case of mothers the severity of the disorder is negatively associated with SOC. In addition the two types of coping strategies are positively associated only in mothers

Table 2. Correlations between child characteristics variables, social support, sense of coherence (SOC), coping strategies and stress in fathers (above diagonal) and mothers (below diagonal)

	1	2	3	4	5	6	7
1. Severity of disorder	—	.414**	-.044	-.239	-.051	.065	.384**
2. Behaviour problems	.423**	—	-.109	-.335*	.062	.276*	.479**
3. Social support	.028	-.042	—	.155	.167	-.151	-.194
4. SOC	-.256*	-.275*	.205	—	-.126	-.686**	-.674**
5. Positive and problem- focused coping	-.005	.198	.181	-.026	—	.131	.193
6. Active avoidance coping	.193	.265*	-.076	-.395**	.340**	—	.530**
7. Stress	.414**	.477**	-.286*	-.702**	.108	.412**	—

** $p < .01$; * $p < .05$

A path analysis was conducted separately for mothers and fathers, resulting in two empirical models. In each model, all of the variables were introduced. The hypothetical models were designed to follow the framework of the double ABCX theoretical model. Graphic paths were constructed while ensuring that the variable relationships were linear. First, examination of normality of variables for each group (mothers and fathers) was performed. The Skewness and Kurtosis test reported departure from normality in a relevant number of variables. In concrete, two variables in the case of mothers' data: social support ($\chi^2 = 7.60$, $p = .022$) and active avoidance coping strategies ($\chi^2 = 11.25$, $p = .001$); and three variables in fathers' data: behaviour problems ($\chi^2 = 9.60$, $p = .001$), social support ($\chi^2 = 8.33$, $p = .020$), and active avoidance coping strategies ($\chi^2 = 19.23$, $p = .010$). These results of

nonnormal variables and the small sample size led us to use Robust Maximum Likelihood method to estimate the models. This method provides the Satorra-Bentler scaled χ^2 fit index (Finch, West, & MacKinnon, 1997; Morata-Ramírez & Holgado-Tello, 2013; Satorra & Bentler, 1994; West, Finch, & Curran, 1995).

To test the goodness of fit of the proposed models we used the following four indices: a) the Satorra-Bentler scaled Chi-squared index, which shows a good model fit when the probability is not significant ($p > .05$); b) the Comparative Fit Index (CFI), in which values greater than .95 represent a good model fit; c) the Normed Fit Index (NFI), in which values greater than .90 are considered acceptable; and d) The Root Mean Square Error of Approximation (RMSEA), in

which values lower than .08 are considered acceptable, and values lower than .05 are considered very good.

Separate path analysis for mothers and fathers were calculated. The fit indices for the stress models are displayed in Table 3. The hypothesised model (Model 1) for stress was tested for mothers (Satorra-Bentler χ^2 (1) = 9.63, p = .002; CFI = 0.91; NFI = 0.92; $RMSEA$ = 0.39). Post hoc model modifications were performed in an attempt to develop a better fitting. First, dispensable, non-significant relationships were dropped to re-estimate the model. The goodness of fit

of this model (Model 2) was: Satorra-Bentler χ^2 (8) = 15.05, p = .058; CFI = 0.92; NFI = 0.87; $RMSEA$ = 0.13). Second, because the regression weight of the positive and problem-focused coping strategies relations with others variables were non-significant, this variable was eliminated and the model re-estimated in an attempt to develop a better fitting and possibly more parsimonious model. The goodness of fit of this model (Model 3) was: Satorra-Bentler χ^2 (13) = 21.21, p = .069; CFI = 0.91; NFI = 0.81; $RMSEA$ = 0.11. This final model is illustrated in Figure 2.

Table 3. The fit indexes for the stress models.

Models of mothers	Satorra-Bentler χ^2 (df)	Probability (p)	Fit Index		
			CFI	NFI	RMSEA
Model 1	9.63 (1)	p = .002	0.91	0.92	0.39
Model 2	15.05 (8)	p = .058	0.92	0.87	0.13
Model 3	21.21 (13)	p = .069	0.91	0.81	0.11
Models of fathers					
Model 1	0.018 (1)	p = .067	1.00	1.00	0.00
Model 2	10.37 (14)	p = .073	1.00	0.92	0.00

Note. CFI = Comparative Fit Index; NFI = Normed Fit Index; RMSEA = Root Mean Square Error of Approximation.

The hypothesised model for stress (Model 1) was tested for fathers (Satorra-Bentler χ^2 (1) = 0.02, p = .067; CFI = 1.00; NFI = 1.00; $RMSEA$ = 0.00). This model was a good fit but it included many non-significant relationships. Post hoc model modifications were performed. Dispensable, non-significant relationships were dropped to re-estimate the model in an attempt to develop a better fitting and possibly safer and more parsimonious model. This model (Model 2) was a good fit (Satorra-Bentler χ^2 (14) = 10.37, p = .073; CFI = 1.00; NFI = 0.92; $RMSEA$ = 0.00). The final model is illustrated in Figure 3.

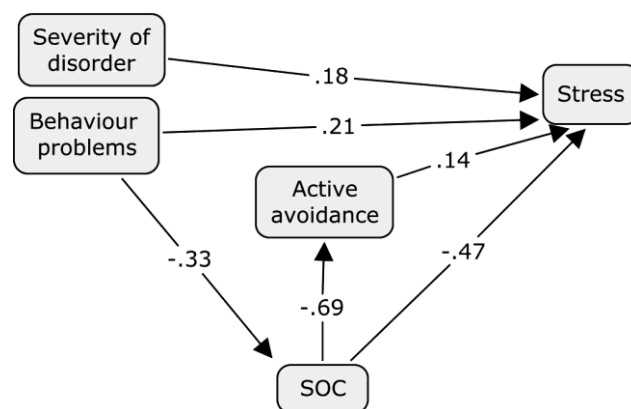


Figure 3. Model of stress in fathers.

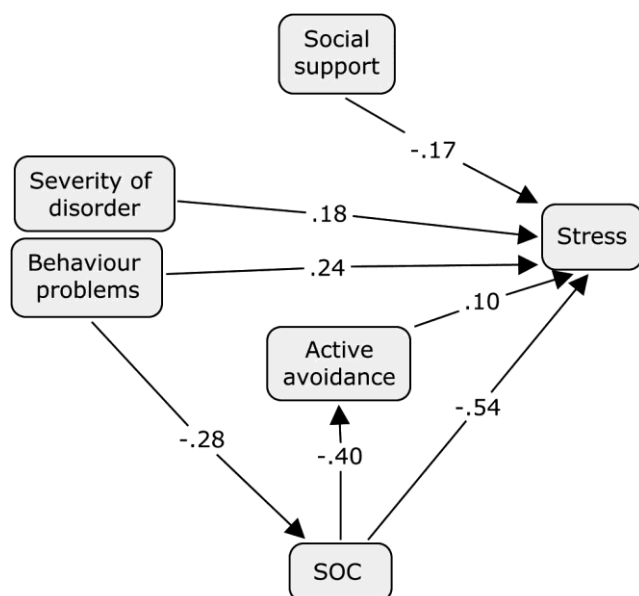


Figure 2. Model of stress in mothers.

The two stress models exhibit both commonalities and differences. We noted that they do not reproduce the exact theoretical model. The empirical models of stress are simpler than the theoretical model: positive and problem-focused coping strategies are not relevant in any of the empirical models and that social support does not play a relevant role in the fathers' stress model. In Table 4, the variables and their effects (direct, indirect and total) in mothers and fathers are presented.

For both models, the characteristics of the individuals with ASD are directly associated with parental stress (see Table 4). Both the severity of the disorder (.18 for mothers and for fathers) and the behaviour problems (.24 for mothers and .21 for fathers) show a positive and direct effect on stress. In addition, the behaviour problems have a positive, indirect effect on the two stress models (.16 for mothers and .19 for fathers). This indirect effect is mediated by SOC; the behaviour problems negatively affect SOC (-.28 for mothers and -.33 for fathers), and SOC has a negative direct effect on

stress (-.54 for mothers and -.47 for fathers). SOC, in turn, has a negative, indirect effect on the two stress models (-.04 for mothers and -.10 for fathers). This indirect effect is mediated by active avoidance coping strategies; SOC negatively affects the active avoidance coping strategies (-.40 for mothers and -.69 for fathers), and active avoidance coping strate-

gies has a positive direct effect on stress (.10 for mothers and .14 for fathers). We found that social support is only relevant to the model of stress in mothers. Social support has a direct negative effect on maternal stress (-.17), indicating that a greater perceived usefulness of social support for mothers is associated with lower levels of stress.

Table 4. Direct, Indirect and Total effects of variables in mothers' and fathers' models.

Mothers									
Variables	Stress			Active avoidance			SOC		
	Dir.	Ind.	Total	Dir.	Ind.	Total	Dir.	Ind.	Total
Severity of disorder	.18		.18						
Behaviour problems	.24	.16	.40		.11	.11	-.28		-.28
Support	-.17		-.17						
Active avoidance	.10		.10						
SOC	-.54	-.04	-.58	-.40		-.40			
Fathers									
Variables	Stress			Active avoidance			SOC		
	Dir.	Ind.	Total	Dir.	Ind.	Total	Dir.	Ind.	Total
Severity of disorder	.18		.18						
Behaviour problems	.21	.19	.40		.23	.23	-.33		-.33
Active avoidance	.14		.14						
SOC	-.47	-.10	-.57	-.69		-.69			

Note. Dir. = Direct effect; Ind. = Indirect effect

To address whether the differences between the individual path models of mothers and fathers were due to group differences in scores for the variables or not, a comparative analysis of mean differences in the variables was performed. The results (Table 5) show no significant differences between mothers and fathers ($N = 118$) on any of the variables except for positive and problem-focused coping strategies

($t_{116} = -3.56, p \leq .001$; Cohen's $d = 0.65$). The data show that mothers use this type of strategy ($M = 17.78$; $SD = 5.35$) more often than fathers ($M = 14.53$; $SD = 4.55$). This effect size interpreted according to Cohen (1988) suggests a medium effect (above 0.50). The post hoc power for this analysis was 0.94 (power equal 0.80 or above is interpreted as sufficient).

Table 5. Means (M), standard deviations (SD) and t-student (t) mean differences for all variables for mothers and fathers

Variables	Mother		Father		t
	M	(SD)	M	(SD)	
Severity of disorder	39.21	(9.06)	39.21	(9.06)	0.00
Behaviour problems	21.01	(14.38)	22.17	(15.86)	0.41
Social support	50.54	(15.40)	49.86	(16.46)	-0.23
Sense of coherence (SOC)	133.03	(23.31)	138.34	(24.40)	1.21
Positive and problem-focused coping	17.78	(5.35)	14.52	(4.55)	-3.56**
Active avoidance coping	3.78	(2.96)	3.32	(3.00)	-0.83
Stress	107.57	(19.82)	103.34	(18.79)	-1.19

** $p < .01$; * $p < .05$

With regard to stress, mothers and fathers show similar levels, at $M = 107.58$ and $M = 103.34$, respectively. However, both groups have an average score of more than 90 points, which is the "clinically significant" cut-off for severe stress. In fact, 79.7 % of mothers and 78% of fathers have scores over 90.

Discussion

The empirical results of this study support partially the use of the double ABCX theoretical model proposed by McCubbin and Patterson (1983) and the use of path analysis to examine the relationships among the variables in this

model. Path analysis allows us to make statements about the patterns of relationships and to identify the direct and indirect effects among a set of variables. The resultant empirical models exhibit a partial fit with the theoretical model. There are patterns of relationships consistent with the model and there are, however, some inconsistencies: positive and problem-focused coping strategies are not relevant in any empirical models, and social support does not play a relevant role in the fathers' stress model. Furthermore, the theoretical model posed three possible types of indirect effects of characteristics of individual with ASD on stress, through the three mediating variables: social support, SOC, and coping strategies. The empirical models only exhibit, the indirect ef-

fect of behaviour problems on stress through SOC, which is consistent in both models.

Separate path analyses examined stress in mothers and fathers, and the results reveal commonalities and differences, providing a more precise explanation of parental stress in mothers and fathers of individuals with ASD. The results of the two models show shared patterns for most variables and the relationships between these variables. Firstly, the characteristics of the individual with ASD have a direct association with parental stress; parents of individuals with severe disorders and serious behaviour problems report more stress than parents of individuals whose characteristics are not as severe. This finding is consistent with the findings of other studies that identify behaviour problems as one of the most important predictors of parental stress (Bishop et al., 2007; Estes et al., 2009; Herring et al., 2006; Tomanik et al., 2004). In addition, behaviour problems exhibit an indirect effect on both models. The level of SOC mediates the effect of the behaviour problems on parental stress. This pattern of this relationship is very clear and consistent. Behaviour problems have a negative effect on SOC and SOC has a negative effect on stress. Parents with a high SOC perceive the situation as more predictable, manageable and meaningful and have less stress than parents with a low SOC. Moreover, SOC has an indirect effect on stress through active avoidance coping strategies. Active avoidance coping strategies have a positive relation to stress, and SOC has a negative association with active avoidance coping. Parents with a low SOC tend to use more active avoidance strategies than parents with high SOC.

The origin of the SOC concept can be found in the theory of salutogenesis, which was proposed by Antonovsky (1987). SOC is conceptualised as:

a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that: 1) the stimuli deriving from one's internal and external environments in the course of living are structured, predictable, and explicable; 2) the resources are available to meet the demands posed by these stimuli; and 3) these demands are challenges worthy of investment and engagement and that life make sense emotionally (Antonovsky, 1987, p. 19).

Although SOC is considered a unitary construct, it can be identified to have three components (comprehensibility, manageability and meaningfulness). People with a strong SOC perceive the world as predictable, manageable and meaningful, and they view stressors as important challenges that are worth facing (Antonovsky, 1992). Some studies have found that SOC is positively related to psychological health and well-being (Cohen & Dekel, 2000; Erickson & Lindström, 2006; Pallant & Lae, 2002; Sagy et al. 1990), and SOC has been shown to have a significant negative association with parental stress (Mak et al., 2007; Oelofsen & Richardson, 2006; Olsson & Hwang, 2002; Pozo et al., 2006).

SOC is a personality characteristic or coping style. It is a stable trait that may be adversely affected by crisis situations

(Antonovsky & Sagy, 1986). The difficulty of raising an individual with ASD can be viewed as an acute stressor that adversely affects the SOC level of the parents. Comparative studies show that the parents of children with ASD have a significantly lower SOC than the parents of children with normal development or the parents of children with intellectual disabilities but without autism (Oelofsen & Richardson, 2006; Olsson & Hwang, 2002). Children with ASD present behaviour problems, including aggression, self-injury, stereotyped behaviours and self-stimulating behaviours, which all represent the strongest predictors of parental stress (Dunlap & Robins, 1994; Richman, Belmont, Kim, Slavin, & Hayner, 2009). The child's challenging behaviours endanger the safety of the child and/or others and are often completely incomprehensible and unpredictable for parents. The child's behaviour problems can affect parental psychological adaptation in multiple ways (Pisula, 2011). Behaviour problems may lead to the parent being socially isolated (Worcester, Nesman, Mendez, & Keller, 2008), significantly fatigued, confused and feeling a loss of the sense of control; these effects can impact the parent's SOC and the protective role of SOC against stress.

Decreasing the severity of behaviour problems should be one of the main objectives of educational programs. Tamarit (1998) indicates that intervention is focused to decrease the probability of the emergence of challenging behaviour and the construction of an alternative behaviour. In this way, parents should understand the characteristics of autism. They should be properly informed of the sensory problems, paradoxical responses to stimulation and susceptibility to sensory overload (Ben-Sasson et al., 2007; Rivière, 2001; 2002; Tomchek & Dunn, 2007; Ventoso, 2000). Parents should also be encouraged to build positive environments that are predictable and to provide their children with basic communication skills and social regulation, which will result in a reduction in their behaviour problems (Robles & Romero, 2011).

An additional finding of this study is the significant role of SOC as a protective factor against stress. Parents with a high SOC present less stress than parents with lower SOC. Professionals could work with families to improve parents' SOC through its three components. Providing parents with clear and consistent information about the characteristics of ASD, explanations of behaviour problems and steps to take after diagnosis and throughout the individual's life could increase the comprehensibility of the problem. Parents should be informed about the support available to them, which can help to manage family demands and empower families to acquire feelings of control and manageability over their lives. Providing parents with a wide variety of coping strategies will enable them to developing the flexibility needed to implement the most appropriate strategy to meet every challenge adaptation. Parents can learn that demands can be perceived as challenges, which can lead to the redefinition of future goals and the reframing of negative con-

cerns, improving the meaningfulness of the situation (King et al., 2006).

With regard to differences between mothers and fathers, we found that social support is relevant only to the model of stress in mothers. For mothers, perceived lack of social support had a direct and negative effect on stress. Mothers who perceived that they have useful and adequate social support to cope with the demands of caring for their child with ASD reported less stress; therefore, a lack of social support is a stress-inducing factor for mothers. In this study, more mothers than fathers were involved in childcare as their main activity compared to fathers. Previous studies of stress in parents of children with intellectual disabilities have found that whereas the fathers' stress was related to their relationship and attachment to the child, the maternal stress was more related to childcare demands (Keller & Honing, 2004; Krauss, 1993; Pelchat, Lefebvre, & Perreault, 2003).

Caring for an individual with ASD entails meeting many needs; a lack of formal support to meet special needs is a source of stress for families. Although autism has been diagnosed in children for more than 66 years, knowledge among health and educational professionals is insufficient. The accessibility of autism-specific services and professional support is still unsatisfactory, and the task of arranging proper support (medical, educational and other services) often falls to the parents (Weiss, 2002). Pisula (2011) found that this problem is present in many countries, including the USA (Watchtel & Carter, 2008), Belgium (Renty & Roegers, 2006) and Poland (Rajner & Wroniszewski, 2000). In Spain, the research conducted by Belinchón et al. (2001) examines the situation and the needs of individuals with ASD in Madrid and the surrounding region. The results indicate that the diagnosis of ASD is delayed by at least a year in 75% of the cases analysed and by more than two years in 54%. For this reason, parents demand more ASD-specific training for professionals. The data also show that there are insufficient educational resources and day care centres, and that individuals with ASD have difficulties in access to employment and integration into the community. Participating parents are concerned about this lack of resources and report high levels of stress and anxiety.

Several limitations of the present study must be taken into account. First, the small sample size limited the number of variables that could be included in the model. Because of this limitation, we used the total scores of the scales, missing in the model specific information provided by the subscales.

Another limitation is the higher average age of individuals with ASD in the sample (14.2 years) and the wide age range (4-38 years). The psychological adaptation of parents who participated in the study may reflect a later stage of accommodation to the challenges of caring for an individual with ASD. Parents at an earlier stage of adjustment might exhibit a different pattern of adaptation. In the present study, the analysis of different models for subgroup of age of individuals with ASD could not be performed because of the size of the sample. For future studies, could be interesting examine models of adaptation comparing age groups, to determine the factors that influence parental adaptations over time.

An additional limitation concerns the external validity of the study. The inclusion criterion for the final sample was that both parents in a family had completed the questionnaires, which standardised the groups of mothers and fathers for family context. The application of this control had the effect of limiting the generalizability of the results. The outcomes can be generalised only to two-parent families. Further studies should use a multidimensional perspective to examine other family types, such as single parent families.

Despite their limitations, the findings of this multidimensional study of parental stress can help professionals to plan interventions in families that include an individual with ASD. Severe stress experienced by the parents of children with ASD can have severe consequences on the parents' physical and mental health (Abbeduto, Seltzer, Shattuck, Krauss, Orsmond, & Murphy, 2004; Kasari & Sigman, 1997; Limiñana & Patró, 2004; Molina-Jiménez, Gutierrez-García, Hernández-Domínguez, & Contreras, 2008; Orejudo & Froján, 2005; Phetrasuwan & Miles, 2009). In this study, 79.7 % of the mothers and 78% of the fathers had scores indicating clinically significant stress levels. Our results are in the same line that the result finding by other studies, which also indicate that parents of children with autism have very high levels of stress (Baker et al., 2005; Belchic, 1996; Dyson, 1997; Herring et al., 2006; Oizumi, 1997; Tomanik et al., 2004); and but that there are no differences in stress between mothers and fathers (Cuxart, 1995; Dewey, 1999; Dyson, 1997; Hastings, Kovshoff, Ward, et al., 2005). Professional attention to factors that facilitate the parents' psychological adaptation and their capacity to respond to the challenges of raising an individual with ASD can have positive and profound consequences on the parents' lives and their relationships with the child and family.

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