



Brief Report: Stress and Perceived Social Support in Parents of Children with ASD

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Abstract

Previous literature has indicated that perceptions of social support (PSS) may be an important predictor of parental stress levels, particularly for parents of children diagnosed with autism spectrum disorders (ASD). The current study implemented structural equation modelling to further investigate the relationship between PSS and parental stress in a sample of 454 parents of children diagnosed with ASD. Results indicate that PSS derived from friends was the most important factor in protecting against stress, with PSS from both a significant other and family appearing to be less pervasive in this regard. In addition, the importance of PSS was further underlined by the finding that it remained a significant predictor of parental stress after controlling for the absence/presence of professional support.

Keywords Autism spectrum disorder · Social support · Stress · Structural equation modeling · Parental stress · Professional support

Introduction

One of the most common disorders currently being diagnosed in children is Autistic Spectrum Disorder (ASD), with estimates of prevalence ranging from .7 to 3.3% across the United States and Europe (Baio 2012; Baio et al. 2018; Christensen et al. 2016; Irish Department of Health 2018; Kim et al. 2011; Waugh 2017; Zablotsky et al. 2015). Due to the unique developmental, behavioural and social challenges associated with ASD, parents of diagnosed children tend to report higher levels of stress than parents of neurotypical children (Barroso et al. 2018; Estes et al. 2009; Johnson et al. 2009; Lee et al. 2017; Montes and Halterman 2007; Phetrasuwan and Shandor Miles 2009; Rivard et al. 2014) and children with other intellectual or developmental disorders (Griffith et al. 2010; Gupta 2007; Schieve et al. 2007). Parental stress and child developmental/behavioural issues have been proposed to interact in a bidirectional or transactional manner across childhood (Baker et al. 2003; Belsky

1984; Gottlieb 2007; Neece et al. 2012; Sameroff 2009). While the exact mechanism underpinning this relationship has been challenged (see Totsika et al. 2013), elevated parental stress levels can encourage poorer adaptive functioning (Cuzzocrea et al. 2016; Hall and Graff 2011, 2012) and thus may serve to exacerbate core and comorbid symptomology associated with ASD.

Social support has been found to be an important protective factor against parental stress and its entailed issues when raising neurotypical children (Farel and Hooper 1998; Koeske and Koeske 1990; Saisto et al. 2008) and children with additional needs, such as autism (Halstead et al. 2018; Handley and Chassin 2008; Onyedibe et al. 2018; Sharpley et al. 1997; Ullrich et al. 2015). Numerous analyses (e.g. Boyd 2002; Gouin et al. 2016; Herman and Thompson 1995) have indicated that informal social support (i.e. from family, friends etc.) may be more effective than formal professional support in protecting against elevated levels of parental stress. In addition, of great import to the current discussion is the recurrent finding that subjective, rather than objective, evaluations of social support (i.e. perceived social support vs. actual social support) may exhibit superior validity with regard to predicting psychological wellbeing (Barrera 1981; Brandt and Weinert 1981; Ke et al. 2010; Sarason et al. 1985; Siedlecki et al. 2014; Solomon et al. 1987; Wilcox 1981).

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Due to the role that perceived social support may exert in diminishing parental stress (and its entailed impact upon child functioning), the importance of further investigating the dynamics of this relationship, particularly for parents of children with additional needs, cannot be understated. Therefore, the current analysis will employ structural equation modelling (SEM) to examine the relationship between perceived social support and parental stress in a sample of parents with children diagnosed with ASD, while also investigating the role of a number of relevant covariates (i.e. presence of professional support, age and gender of child, number of children with ASD in household, ASD severity level) in influencing this relationship.

Method

Participants

The current sample consisted of 454 adults, all of whom had at least one child diagnosed with ASD. Participants were asked only to participate if their child was under 18, was living at home and had been clinically diagnosed with ASD.

Materials

Autism Parenting Stress Index (APSI; Silva and Schalock 2012)

The APSI is a 13-item Likert-style questionnaire designed to measure the impact of specific core and co-morbid symptoms associated with ASD on the stress levels of a parent. While the APSI was originally conceived as a three-factor model, consisting of stress caused by core autism behaviours (e.g. social development issues, communication skills, social acceptance), co-morbid behaviours (e.g. self-injurious behaviours, aggressive behaviour, difficulty making transitions) and co-morbid physical problems (e.g. sleep, toilet training, dietary issues), exploratory factor analysis conducted by Silva and Schalock (2012) indicated a four-factor model, with co-morbid physical problems being subdivided in two separate factors (bowel/toilet training issues and sleep/dietary issues) adequately represented the structure. All items require the parent to rate the degree of stress that they experience as a result of such issues on a 5-point scale ranging from 0 (not stressful) to 5 (so stressful sometimes we feel we can't cope). Initial validation of the APSI found a satisfactory internal consistency (Cronbach's alpha) except for the co-morbid physical problems factor ($\alpha_c = .67$; Silva and Schalock 2012). In the current study, the internal consistency of the global scale was .85 (core autism behaviour = .78; co-morbid behaviours = .80; co-morbid physical problems = .65). The internal reliability of the co-morbid

physical problem subscale was below satisfactory; however, this is likely to be underestimated due to the Cronbach's alpha statistic favouring measures with a larger number of items (Graham 2006).

Multidimensional Scale of Perceived Social Support (MSPSS; Zimet et al. 1988)

The MSPSS is a 12-item Likert-style questionnaire which aims to measure an individual's perception of support from Family (3 items), Friends (3 items) and a Significant Other (3 items). All questionnaire items present participants with a statement related to self-rated levels of support, commitment and reliability felt from each of these three sources (e.g. "My family really tries to help me") alongside a 7-item scale of agreement ranging from 1 (very strongly disagree) to 7 (very strongly agree). Previous research has demonstrated satisfactory internal consistency for the MSPSS (Stewart et al. 2014). Similarly, the Cronbach's alpha in the current study was excellent ($\alpha_c = .94$), as were the different domains (significant other = .94; family = .95; friends = .94).

Procedure

Participants were sourced through advertisement on social media support groups for parents of children with ASD living in Ireland. Upon consenting to participate, participants were required to complete a small number of demographic questions (i.e. age and gender of child, number of children with ASD, parent-rated diagnosis severity and whether professional support is being received), followed by the APSI and MSPSS questionnaires. Overall administration time was approximately 10 min, with all questionnaires being completed via an online link.

Analytical Plan

Structural equation modelling (SEM) was used to examine the relationship between perceived social support ('significant other', 'family', and 'friends') and parental stress (relative to 'core autism behaviours', 'co-morbid behaviours', and 'co-morbid physical issues'). SEM is advantageous as it attempts to parse out measurement error, thus providing more accurate parameter estimates (Bollen 1989). Following the guidelines set forth by Anderson and Gerbing (1988), it was first necessary to establish the validity of the measurements models using a series of confirmatory factor analyses (CFA), before assessing the structural model.

Data was analysed using Mplus 7.4 (Muthén and Muthén 2012) and the models were estimated using the robust maximum likelihood (MLR) estimator. In order to determine the adequacy of the measurement and structural models, multiple goodness-of-fit indices

(Hu and Bentler 1999) were assessed. A non-significant χ^2 indicates excellent model fit, however, this test is heavily influenced by sample size therefore a significant result ($p < .05$) should not lead to the rejection of a model (Tanaka 1987). Comparative Fit Index (CFI; Bentler 1990) and Tucker-Lewis Index (TLI; Tucker and Lewis 1973) values $> .90$ are indicative of adequate model fit and values $> .95$ indicate excellent model fit. Additionally, Root Mean Square Error of Approximation (RMSEA; Steiger 1990) and Standardised Root-Mean-Square Residual (SRMR; Jöreskog and Sörbom 1981) values $< .08$ and $< .05$ suggest adequate and excellent model fit, respectively. A number of covariates were also included: child's age, child's sex, parent-rated severity of ASD (mild, moderate, or severe), currently receiving professional support, and having > 1 child with ASD. The proportion of missing data for all of the individual study variables ranged from 0 to 8.8%, with a mean of 3.6%. Missing data were found to be missing completely at random (MCAR), as indicated by Little's MCAR test ($\chi^2 [1019, N = 454] = 1082.65, p = .081$). Missing values were handled using the robust full information maximum likelihood procedure, as this allows parameters to be estimated using all information available.

Results

Descriptive Statistics

Table 1 summarises the descriptive statistics for the continuous variables of the model (i.e. mean, median, standard deviation [SD], and range).

Measurement Model: Multidimensional Scale of Perceived Social Support (MSPSS)

The three-factor model ('significant other', 'family', and 'friends') of the MSPSS provided an excellent fit to the data ($\chi^2 [51] = 148.27, p < .001$; CFI = .97; TLI = .96; RMSEA = .07 [90% CI .06, .08]; SRMR = .03). Inter-factor correlations ranged from .49 to .70, and the standardised factor loadings for all items were statistically significant ($p < .001$), ranging from .85 to .93.

Measurement Model: Autism Parenting Stress Index (APSI)

The APSI has been conceptualised as a three-factor model, however, was also found to represent a four-factor structure. Therefore, both the three- and four-factor

Table 1 Sample characteristics and descriptive statistics of the current study

Sample characteristic	% (n)	Mean (95% CI)	Median	SD	Range
Social support					
Significant other		17.32 (16.56/18.08)	18.00	7.79	4–28
Family		14.64 (13.89/15.40)	14.00	7.79	4–28
Friends		13.19 (12.50/13.87)	12.50	7.12	4–28
ASD parental stress					
Core autism behaviours		11.47 (11.02/11.92)	11.00	4.75	0–25
Co-morbid behaviours		7.40 (6.99/7.80)	7.00	4.31	0–20
Co-morbid physical issues		6.40 (6.16/6.79)	6.00	4.15	0–20
Child's age		8.17 (7.78/8.57)	7.00	4.30	2–29
Child's sex					
Male	75.7 (337)				
Female	24.3 (108)				
ASD severity					
Mild	41.0 (186)				
Moderate	43.2 (196)				
Severe	12.6 (57)				
Professional support					
No	43.6 (198)				
Yes	55.7 (253)				
Number of children with ASD					
1	81.7 (371)				
> 1	18.3 (83)				

95% CI 95% confidence intervals, SD standard deviation

models were evaluated. It was found that both the three-factor ($\chi^2[62] = 345.13$, $p < .001$; CFI = .83; TLI = .79; RMSEA = .10 [90% CI .09, .11]; SRMR = .10) and four-factor ($\chi^2[59] = 339.85$, $p < .001$; CFI = .84; TLI = .78; RMSEA = .10 [90% CI .09, .11]; SRMR = .10) solutions did not adequately represent the data. After inspection of the modification indices, it was found that this model misfit was largely due to a substantial residual covariance between item 13 (“Concern for the future of your child living independently”) and item 12 (“Concern for the future of your child being accepted by others”). This residual covariance was believed to be substantively meaningful and thus, the model was re-specified to include the residual covariance between the two items. Due to the similar model fit between the three- and four-factor models, the model was re-evaluated as a three-factor model (‘core autism behaviours’, ‘co-morbid behaviours’, and ‘co-morbid physical issues’) on the grounds of parsimony. The majority of model fit indices indicated adequate fit to the data ($\chi^2[61] = 222.50$, $p < .001$; CFI = .91; TLI = .88; RMSEA = .08 [90% CI .07, .09]; SRMR = .06). Inter-factor correlations ranged from .66 to .73, and the standardised factor loadings for all items were statistically significant ($p < .001$), ranging from .48 to .86.

Structural Model: Perceived Social Support and Parental Stress

The SEM model of perceived social support and parental stress provided satisfactory fit to the data ($\chi^2[369] = 765.38$, $p < .001$; CFI = .94; TLI = .93; RMSEA = .05 [90% CI .05, .06]; SRMR = .06) and explained 27% of variance in parental stress relative to ‘core autism behaviours’, 13% of variance

relative to ‘co-morbid behaviours’, and 33% of variance relative to ‘co-morbid physical issues’.

While controlling for covariates, perceived social support from friends was inversely associated with parental stress relative to all three latent factors: i.e. ‘core autism behaviours’ ($\beta = -.22$, $p = .002$); ‘co-morbid behaviours’ ($\beta = -.15$, $p = .024$); ‘co-morbid physical issues’ ($\beta = -.19$, $p = .025$). Moreover, perceived social support from an individual’s significant other was also inversely associated with parental stress relative to ‘co-morbid physical issues’ ($\beta = -.22$, $p = .014$). For all parameter estimates see Table 2.

Discussion

The current analysis reports a significant association between perceived social support and levels of parental stress for those raising children diagnosed with ASD. Specifically, it appears that the most pervasive source of support may be derived from friends, as there was an inverse association between perceived friend support and all three APSI factors (i.e. core autism behaviours, co-morbid behaviours, co-morbid physical issues). In contrast, perceived support from a significant other was only inversely associated with one of these three factors (co-morbid physical issues), while perceived family support was not associated with any APSI factor. The current results therefore strongly emphasise the relative importance of perceived friend support, which is of particular interest due to the fact that much of the previous research in this field tends to centre upon the influence of spousal/partner and/or family as the primary sources of

Table 2 Standardised and unstandardised parameter estimates for the effects of perceived social support and covariates on parental stress (APSI)

	Core autism behaviours		Co-morbid behaviours		Co-morbid physical issues	
	B (SE)	β (SE)	B (SE)	β (SE)	B (SE)	β (SE)
Perceived social support						
Significant other	-.06 (.04)	-.13 (.09)	-.06 (.05)	-.09 (.08)	-.12* (.05)	-.22 (.09)
Family	.01 (.04)	.03 (.10)	-.02 (.06)	-.03 (.09)	.05 (.05)	.11 (.10)
Friends	-.12** (.04)	-.22 (.07)	-.12* (.05)	-.15 (.07)	-.11* (.05)	-.19 (.08)
Covariates						
Child’s age	-.01 (.01)	-.04 (.06)	-.01 (.02)	-.04 (.05)	-.04** (.01)	-.19 (.07)
Child’s sex ^a	-.02 (.10)	-.01 (.05)	-.22 (.14)	.00 (.05)	.07 (.13)	.03 (.06)
ASD severity	.49*** (.08)	.40 (.06)	.36*** (.10)	.21 (.06)	.53*** (.09)	.37 (.06)
Professional support ^b	-.14 (.09)	-.08 (.05)	-.26* (.12)	-.11 (.05)	-.27* (.11)	-.14 (.06)
> 1 child with ASD ^c	.21 (.13)	.10 (.06)	.40* (.17)	.13 (.06)	.34* (.15)	.14 (.06)

Statistical significance: * $p < .05$; ** $p < .01$; *** $p < .001$

B unstandardised estimates, β standardised estimates, SE standard error

^aSex coded as 0 = male, 1 = female

^bProfessional support coded as 0 = not currently receiving professional support, 1 = currently receiving professional support

^cNumber of children with ASD coded as 0 = one child with ASD, 1 = more than one child with ASD

social support (e.g. Ekas et al. 2010; Goedeke et al. 2019; Herman and Thompson 1995) (Fig. 1).

Upon analysis of covariates, ASD severity was found to significantly predict parental stress derived from all three factors. Stress derived from co-morbid behaviours was associated with raising more than one child with ASD, and negatively associated with receiving professional support. Stress derived from co-morbid physical issues was negatively associated with the presence of professional support and child age, the latter of which may be explained by the relative pertinence of toilet training issues for younger children. This APSI factor was also positively associated with number of ASD children being raised.

Further underlining the relative importance of perceptions of social support (Barrera 1981; Brandt and Weinert 1981; Sarason et al. 1985; Solomon et al. 1987; Wilcox 1981), the current analysis found that perceived social support remained a consistent significant predictor of parental stress, despite the presence of professional support. In addition, it is also important to note that professional support was not predictive of reduced stress relating to core autism behaviours. In terms of stress levels, Silva and Schalock (2012) report that these are the two areas in which ASD parents tend to differ most significantly from parents of both neurotypical children and children with other developmental disabilities. Therefore, the finding that receipt of professional support was not associated with reduced stress levels regarding such issues is noteworthy. This may be rendered more significant due to the finding that when professional support is provided but not deemed useful or beneficial, there may be further

negative implications for the psychological wellbeing of parents (Konstantareas and Homatidis 1989; Smith et al. 2012).

There are several limitations associated with the above findings that should be acknowledged. First, the CFA results revealed concerns regarding the validity of the APSI, largely due to a residual covariance between items 13 and 12. Future studies should aim to address this issue, perhaps by removal or rephrasing of the item(s), to further enhance the psychometric attributes of this measure. Second, the current study was cross-sectional in nature, thus precluding any causal inferences regarding the temporal ordering of the model assessed (i.e. poor social support leads to increased parental stress). Future studies may investigate the role of parental factors, such as general psychological wellbeing, personality variables and gender, as well as the role non-specific stressors (e.g. financial stress, relationship satisfaction). Third, only self-report measures were used for the purposes of this study. Despite the previously discussed advantages of administering subjective measures in this domain, it could be argued that the administration of both subjective and objective indices of parental stress (such as biomarkers), autism severity and professional support (such as detailed data on service access) may have provided a slightly more nuanced treatment of the research question.

In conclusion, the current investigations harbours implications of great importance to clinical interventions aimed at reducing levels of stress experienced by parents of children with ASD. The current results indicate that perceived informal social support, particularly that received from friends, can exert a substantial positive effect in alleviating

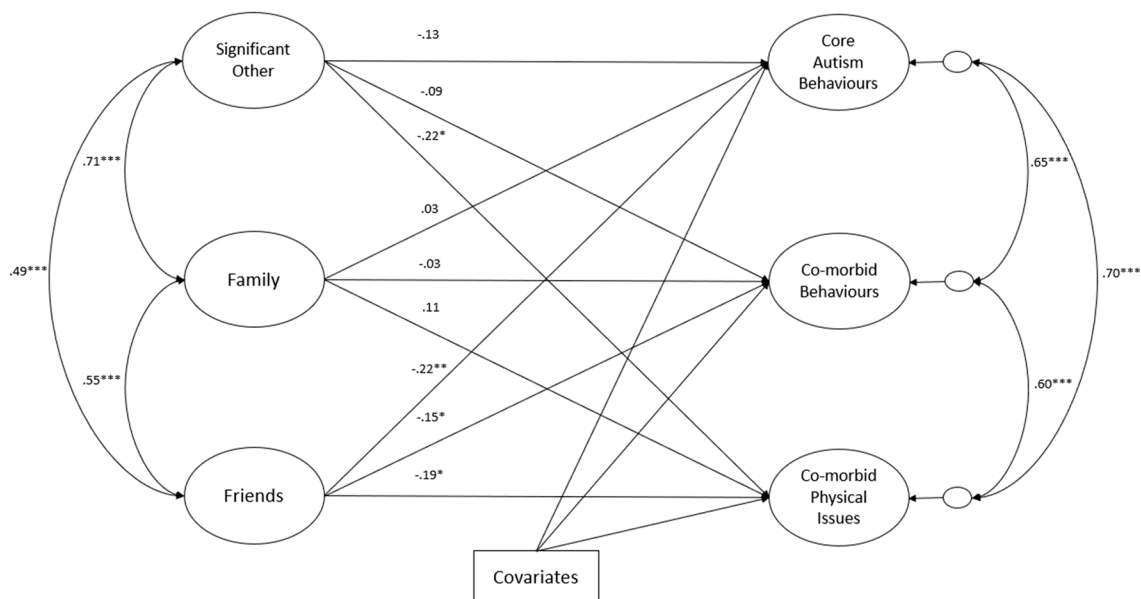


Fig. 1 Structural model illustrating the association (standardised estimates) between social support (‘significant other’, ‘family’, and ‘friends’) and parental stress (relative to ‘core autism behaviours’,

‘co-morbid behaviours’, and ‘co-morbid physical issues’). Individual exogenous covariate pathways are omitted for visual clarity. Statistical significance: * $p < .05$; ** $p < .01$; *** $p < .001$

levels of parental stress commonly associated with raising a child with ASD. Not only was this source of support found to outperform formal professional support in this regard, but furthermore, the current results suggest that such professional support may be proving inadequate in contributing to the maintenance of the psychological well-being of parents of children with ASD.

Author Contributions KD and DC conceived and designed the study, with KD completing data collection and preliminary analyses. DC functioned research supervisor, corresponding author and was primarily responsible for writing and submitting the manuscript. RF conducted the statistical analysis and composed the results section of the manuscript. All authors contributed to responding to peer review recommendations.

Compliance with Ethical Standards

Conflict of interest The authors declare no conflict of interest in relation to the current study.

Ethical Approval This current design was approved by the ethical review board of the first and third authors' affiliated institution and was conducted in line with ethical guidelines as outlined by the Psychological Society of Ireland.

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