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How perceived support relates to child autism symptoms and care-related stress in parents caring for a child with autism

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ABSTRACT

Background: Caring for a child with autism spectrum disorder (ASD) may be stressful and subsequently affect parents' ability to manage their child's symptoms. In this research, we explore the effects of perceived levels of support on parents' care-related stress and on ASD symptoms.
Method: Participants (n = 585) completed an online survey which included ratings of support (partner, family, friend, professionals), how they perceived their child's symptoms, their care-related stress, and ratings of their child's interventions.
Results: Results indicate that parents perceive partners and families as providing greater support than friends and professionals. However, perceptions of family support decrease with both parent and child age. Perceived family support did not appear to influence parents' perceptions of their child's symptoms, although partner support moderated the relationship between particular symptom subsets and care-related stress. Professional support was related to a decrease in care-related stress levels. Finally, some sources of support were associated with perceived effectiveness and stress reduction in relation to specific interventions.
Conclusions: Partners and family provide an important support role for parents yet may need education and support to assist them in this role on an ongoing basis. Understanding how professionals can better support parents in their caregiving role is also important.

1. Introduction

Autism spectrum disorder (ASD) is a developmental disability characterised by deficits in social communication and interaction (including responding inappropriately in conversations, misreading nonverbal interactions, or having difficulty forming age-appropriate friendships), and restrictive, or repetitive patterns of behaviour (such as an overdependence on routines, high sensitivity to environmental changes, or intense focus on inappropriate items) (American Psychiatric Association (APA), 2013). ASD encompasses several disorders that were previously defined in the DSM-IV-TR as separate disorders, including autistic disorder, pervasive developmental disorder not otherwise specified, and Asperger Syndrome (APA, 2000). ASD is thus a broad diagnostic category with the symptoms of those diagnosed varying widely, with some individuals displaying only mild symptoms and impairment and others displaying severe symptoms that cause significant impairment in social and occupational/educational functioning.

While the severity of ASD symptoms may vary widely, caring for a child with ASD has routinely been reported as highly stressful, and associated with a higher incidence of parental mental health issues (such as depression and anxiety), the experience of negative emotional reactions (including anger, grief, disappointment, guilt), lower quality of life, and marital or partner relationship strain

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(Khanna, Madhavan, & Smith, 2011; Mao, 2012; Zablotsky, Bradshaw, & Stuart, 2013). Further, while parenting stress is typically reported for those caring for children with any type of developmental disability, several authors (e.g., Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Stuart & McGrew, 2009) suggest that the stress associated with caring for a child with ASD exceeds that associated with caring for a child with another developmental delay. This may be due to the challenge and complexity of the particular symptoms associated with ASD (Ludlow, Skelly, & Rohleder, 2011; Seymour, Wood, Giallo, & Jellett, 2013), the impact of ASD symptoms on family life and the adjustments required to accommodate them, the challenges associated with accessing support from health, education and social services, and negative and judgemental public reactions (Seymour et al., 2013). Stress may be associated not only with negative outcomes for parents' mental health and psychosocial wellbeing but may also make it more difficult for parents to manage the behaviours associated with ASD appropriately. This, in turn, may potentially contribute to symptom increase (Seymour et al., 2013).

Several studies have sought to identify moderators of parenting stress, including individual characteristics of the child and parent such as age (Derguy, Bailara, Michel, Roux, & Bouvard, 2016; McStay, Dissanayake, Scheeren, Koot, & Begeer, 2014). As children age, different challenges associated with key developmental stages may present, and yet studies about the effect of children's age on parenting stress have been inconsistent (Derguy et al., 2016; Duarte, Bordin, Yazigi, & Mooney, 2005; Falk, Norris, & Quinn, 2014; Rivard, Terroux, Parent-Boursier, & Mercer, 2014). Similarly, while some studies indicate that younger parents of children with ASD are more likely to demonstrate higher stress levels, other studies have been inconclusive (Falk et al., 2014; Lau, Gau, Chiu, & Wu, 2014). Derguy et al. (2016) emphasise that an ecological approach to understanding parenting stress should be adopted, acknowledging the impact of both individual as well as environmental factors, such as social support.

Indeed, several studies have suggested that social support may be an important moderating variable for parenting stress (Seymour et al., 2013; Smith, Seltzer, Tager-Flusberg, Greenberg, & Carter, 2008). Common sources of informal support are partner/spouse, family, and friends, and formal support networks are typically defined as clinicians and health professionals. The different sources of social support vary in their effectiveness as a coping strategy. For example, King, King, and Rosenbaum (1999) report that support from formal sources (professionals such as doctors and therapists) assisted parents in coping with the demands of a child with an intellectual disability, and Hastings (1997) reported similar findings in relation to informal sources, such as family support.

In terms of research related specifically to ASD, studies on parents of children with ASD indicates that there may be a negative association between receiving support from friends and family, and parenting stress levels, negative emotional reactions, and mental health problems (Dunn et al., 2001; Herring, Gray, Tonge, Sweeny, & Einfeld, 2006; Murphy, Christia, Caplin, & Young, 2006; Plant & Sanders, 2007; Sawyer et al., 2010). Family and friend support may also mediate the relationship between caregiver burden and quality of life (Marsack & Samuel, 2017). Such support may be instrumental in assisting parents directly in progressing their child's interventions, and a reduction in parenting stress as a consequence of support may in turn, positively impact intervention outcomes (Osborne, McHugh, Saunders, & Reed, 2008). Support from family and friends, for example, has been associated with an ability to resolve difficult parenting situations (Ekas, Lickenbrock, & Whitman, 2010; Murphy et al., 2006). Other sources of informal support, such as 'neighbourhood social support', have similarly been associated with lower risk of parental depressive symptoms (Zablotsky et al., 2013). Low levels of family and other sources of informal support, on the other hand, have been found to be associated with higher levels of psychological distress for mothers of children with ASD (Boyd, 2002; Bromley, Hare, Davison, & Emerson, 2004; Pozo & Sarriá, 2014) as well as with higher levels of reported autism symptomology (Hastings et al., 2005). The active seeking of support may thus be an important moderator strategy in the relationship between stress and quality of life (QOL) (Dardas & Ahmad, 2015; Marsack & Samuel, 2017).

Research has also explored the effect of perceived support from professionals on parental stress levels, with some suggesting an association between high levels of support and an enhancement of parents' wellbeing and a decrease in their stress levels (Mak & Kwok, 2010; Plant & Sanders, 2007). Several reasons for the positive effects of support have been proposed, including having a sense of being understood, support with daily schedules (Ludlow et al., 2011; Sawyer et al., 2010; Stuart & McGrew, 2009) and assistance in dealing with difficult behaviours (Bitsika & Sharpley, 2004; Plant & Sanders, 2007).

Derguy et al. (2016) however, further highlight the need to consider how individual child and parent factors (such as age) and environmental factors, such as social support, interact and moderate the effects on parenting stress. For example, Tehee, Honan, and Hevey (2009), suggest that access to support and perceived efficacy of support may vary according to child characteristics such as age, with their research indicating that parents of children aged between 11–14 years reported better quality support than younger or older children. Thus, the association of child and parent characteristics, support and parenting stress is also important to consider (McStay et al., 2014).

The influence of support from different sources and the relationship to self-rated parental stress for parents of children with ASD has received little research attention. Further, the relationship between support, parental stress and parent-rated ASD symptomology, and the moderating effects of age, remains a relatively unexplored area however. In this study, we explore the relationship between perceived social support and self-rated parenting stress, and between perceived support and parent-rated child ASD symptoms. We explore the various potential sources of support: partner, family, friends and professionals, both overall and in relation to particular interventions, as well as the moderating effects of a number of variables, including age of child and parent, and parent education.

2. Methods

2.1. Participants

Five hundred and eighty-five parents, of which 527 were females, participated. The mean age of the sample was 44.9 years

Table 1
Characteristics of parents and their children (N = 583).

		Frequency	Percent
Parents' gender			
	Female	527	91%
	Male	53	9%
Parents' age band			
	Up to 19	2	< 1%
	20–29	8	2%
	30–39	123	22%
	40–49	294	53%
	50–60	130	22%
Parents' ethnicity			
	NZ European	438	74.9%
	European	32	5.5%
	Maori	29	5%
	Pasifika	15	2.5%
	Other	53	12.1%
Parents' education			
	Secondary	143	25%
	Technical College	94	16%
	University	273	47%
	Other	72	12%
Child's gender			
	Male	480	82%
	Female	103	18%
Child's age band (years)			
	Up to 5	221	38%
	5–10	302	52%
	11–15	51	9%
	15–20	9	2%
Source of diagnosis			
	Medical doctor	55	9.4%
	Clinical Psychologist	10	1.7%
	Paediatrician	398	68.2%
	Other	120	20.5%

(SD = 7.76, min = 19, max = 62), with 567 participants identifying themselves as biological parents who had cared for their child with ASD from birth. The mean age of their child with ASD was 12.02 years (*SD* = 5.85, min = 2, max = 19), with 482 of parents caring for sons, and 103 for daughters. Overall, 153 of the children had no siblings, 274 had one sibling, 107 had two siblings, and 47 had three-or-more siblings. All parents reported that their children had received a formal medical diagnosis of ASD from a medical professional, the most common being a paediatrician. Approximately 37% of children (n = 168) possessed a comorbidity, with anxiety disorder (n = 104), ADHD (n = 78), Global Developmental Delay (n = 38)/and Intellectual Disability (n = 27) being the most reported. Table 1 provides a detailed profile of the sample.

2.2. Measures

2.2.1. ASD core symptoms

Parent ratings of their child's core ASD symptoms were based on the Autism Impact Measure (AIM) developed by Kanne et al. (2014). The AIM is an 82 item inventory indexing core ASD symptoms in terms of the impact they have on child function as-well-as the frequency of their occurrence. The impact and frequency subscales use the same 41 items, and to reduce the length of the AIM scale Kanne et al. (2014) subjected these 41 items to a factor analysis. They subsequently reported a four-factor solution made up of 25 items, reducing the AIM scale to 50 items, 25 items each for the Impact and Frequency scale respectively. In this study only the abbreviated 25 item impact subscale (here-on the ASD-Impact Scale) was used, utilising the abbreviated item descriptors presented in Kanne et al.'s (2014) Table 4. As such, questions around the frequency of symptom occurrence were not asked as they were not considered conceptually relevant to the study, and Kanne et al.'s (2014) data indicate the presence of collinearity between the Impact and Frequency subscales for three of the four AIM subscales. As used in the current study, the ASD-Impact scale consists of 25 parent-rated items probing core ASD symptoms along four subdomains: repetitive behaviours (8 items), odd/typical behaviours (5 items), communication/language impairment (5 items), and social/emotional reciprocity deficits (7 items). Parents were required to make ratings using a 5 point Likert-type scale ranging from 1 (Not at All) to 5 (Severe). All ratings were referenced to the previous fortnight.

Table 2
Means (M) and standard deviations (SD) of the 13 items making up the ASD care-related stress scale. Means are ranked from highest to lowest, with higher means indicative of greater stress.

Item	*M*	*SD*
Advocating on behalf of him/her	3.72	1.27
Doing therapy/educational activities	2.84	1.44
Cleaning up after him/her	2.84	1.27
Attending medical/therapy appointments	2.77	1.55
Helping and supervising at mealtimes	2.75	1.31
Settling him/her at bedtime	2.64	1.43
Transporting to appointments	2.57	1.44
Filling out forms relating to him/her	2.56	1.39
Helping and supervising with toileting	2.23	1.33
Getting him/her ready for bed	2.21	1.36
Helping and supervising with dressing	2.17	1.47
Giving medication to him/her	2.13	1.54
Helping and supervising with bath time	2.02	1.30

2.2.2. *ASD care-related stress scale*

Plant and Sanders's (2007) Australian-developed 22-item care-related stress scale was shortened and used to measure parenting stress relating from challenging tasks typically encountered by parents of a child with ASD (see Table 2). This scale was selected for the current study as it was judged to be more culturally appropriate than the Autism Parenting Stress Index (Silva & Schalock, 2012), given that Australia and New Zealand are geographical neighbours and share close cultural and societal ties. From their scale, the ten tasks with the highest mean stress scores were identified for both men and women. Taking these two sets of ten tasks for males and females, a 13-item ASD Care-Related Stress Scale was created, where seven of the items overlapped across the genders. The justification for the abbreviation of the original scale was to target those tasks that participants found most stressful while minimising the number of items in the scale. A 7-point Likert-scale ranging from 1 (Not at all Stressful) to 7 (Very Stressful) was used to indicate the stress experienced while undertaking these tasks. A "not applicable" option was also included, and N/A responses ranged from 1.4% to 3.2% across the 13 items. As analysed, a mean item score was calculated for each participant, theoretically ranging from one to seven, with the N/A responses discarded.

2.2.3. *Support for parents*

The availability of the parents' support network was measured using a four-item scale generated for the purpose of this study. Participants were required to rate how much support they felt they received from their partner, family, friends and health professionals (e.g., doctor, therapist) using a 7-point Likert-scale ranging from 1 (Not Supported) to 7 (Very Supported). A "not applicable" option was also available for non-existent sources of support.

2.2.4. *Engaged interventions*

Keeping within the New Zealand treatment context, parents were asked if their child with ASD had been exposed to any of five interventions in the past or presently, and if so, how helpful the intervention was, or is, in terms of effect on ASD symptoms (1 = No improvement, 7 = Substantial Improvement) and also relieving their parent-related stress (1 = Not Helpful, 7 = Extremely Helpful). The five interventions, which were contextually defined in the survey to ensure that parents did not confuse interventions with overlapping therapeutic components, were speech language therapy (SLT), behavioural therapy (BT), intensive Applied Behavioural Analysis (iABA) therapy, occupational therapy (OT), and dietary interventions (DI). Formal definitions of the five interventions can be found in Shepherd, Landon, and Goedeke (2018), and were chosen on the basis that they constitute the frontline and most common interventions available in the New Zealand.

2.3. *Procedure*

A nationwide ASD support agency located in New Zealand distributed e-mail invitations to parents caring for an individual with ASD. The invitations provided the parents with a link to the online questionnaire. A Participant Information Sheet was attached to the email invitation and downloadable from the online version of the questionnaire. The online survey remained open for 40 days. This research was approved by the Auckland University of Technology Ethics Committee (Number: 16/183).

2.4. *Data analyses*

Analysis commenced with the calculation of descriptive statistics (means and standard deviations) and reliability coefficients (Cronbach's alphas: αc) for the key variables. Next, exploratory analyses were undertaken to uncover links between the four categories of support and participant characteristics such as their gender, age, level of education, child comorbidities, and gender/age of their child with ASD. Preliminary correlational analyses estimated the associations between key variables and determined if sufficient relationships existed to undertake further regression analyses. For example, sibling number was not found to significantly covary with parenting stress or the ASD-Impact Scale, and was therefore not subjected to further analyses. Likewise, a one-way ANOVA ($F(94, 222) = 1.566$, $p = .184$) revealed no differences across child comorbidity, and so this variable was also excluded. All correlational analyses were undertaken controlling for participant age, education, and age of child with ASD. These initial analyses were undertaken using the Statistical Package for the Social Sciences (SPSS, V.23).

The relationship between core ASD symptoms (i.e., ASD-Impact Scale) and parenting stress (i.e., the ASD care-related stress scale) was modelled using a linear multiple regression model. An initial model probed the main effects of participant age and education, child age, the four ASD-Impact subscale scores and the four measures of parent support: family, friends, partners and health professionals. To simplify the interpretation of results the support scores were dichotomised using a median split, producing low support or high support categories. A second model, formulated to assess all moderation effects collectively, expanded the first model by adding the 16 interaction terms corresponding to each combination of ASD-Impact subscale and dichotomised support moderator. Stepwise model selection based on Akaike's information criterion was used to eliminate variables (besides the ASD-Impact Scale and support variables) that were not required to be retained in the model for the purpose of confounder adjustments. Occasional missing values in covariates were imputed using multivariate imputation by chained equations, a technique that uses known observations to choose the most likely value of missing values in covariates (van Buuren & Groothuis-Oudshoorn, 2011). This allowed the models to be based on all cases. Model assumptions regarding the independence and normality of residuals were evaluated for each model and found to be acceptable. No evidence of multicollinearity in either main effects model was seen. The models containing interaction terms must necessarily exhibit some multicollinearity but this was handled correctly in the software by appropriately inflating the estimates of the standard errors. Moderation analyses were conducted using R version 3.2.3 (R Core Team, 2015).

To investigate if social support is associated with how parents perceive interventions to effectively reduce their parenting stress levels and their child's symptom severity, a total of ten hierarchical multiple regressions were performed, two for each intervention type. The dependent variable was parent-assessed intervention effectiveness or how the intervention impacted their care-related stress. The first stage of the model included parent age and level of education, and child age. The second step included all four of the social support variables (not dichotomised), with the R^2 change statistic indicating if the addition of support induced better (or worse) perceptions of intervention outcomes. Model assumptions were confirmed prior to the analyses, which were undertaken in SPSS (V.23).

3. Results

3.1. Sources of support

Mean support was calculated for family ($M = 2.68$, $SD = 1.36$), friends ($M = 2.17$, $SD = 1.18$), partners ($M = 3.31$, $SD = 1.78$), and health professionals ($M = 2.31$, $SD = 1.15$), and compared using a repeated measures ANCOVA ($F(3,435) = 99.869$, $p < .001$, $\eta p^2 = .159$) controlling for participant age, education, and age of child with ASD. Pairwise comparisons, adjusted with Bonferroni corrections, were all significant, with the exception of the friends and health professional pairing ($p = .075$). Furthermore, a main effect of parent age ($F(1,555) = 45.484$, $p < .001$, $\eta p^2 = .025$) and child age ($F(1,568) = 48.631$, $p < .001$, $\eta p^2 = .026$) was noted. Notable correlation coefficients in Table 3 are those between family support and both parent ($r = -.187$) and child ($r = -.118$) age, which were negatively correlated, and between child age and partner support ($r = -.163$). A main effect of parent education was not found across the support categories ($F(4,564) = .630$, $p = .240$, $\eta p^2 = .004$).

Table 3

Scale means (M), standard deviations (SD) and the Cronbach's alpha (α_c) for the ASD-Impact Scale, social support measures, and the ASD Care-Related Stress Scales. With the exception of the demographic measures, the final four columns show partial correlations controlling for parent age and education, and age of child.

				Partial Correlation Coefficients			
	M	*SD*	α_c	Family	Friends	Partner	Professionals
Demographic Measures							
Parent Age	*44.9*	*7.75*	–	$-.187^{**}$	$-.056$	$-.09^{*}$	$-.10^{*}$
Child Age	*12.0*	*5.85*	–	$-.118^{*}$	$-.047$	$-.163^{*}$	$-.08$
ASD-Impact Subscales							
Restricted/Ritualized Behaviour	2.94	1.28	.820	$-.049$	$-.012$	$-.114^{*}$	$.096^{*}$
Communication/Language	2.85	1.47	.858	.017	$.086^{*}$	.055	.046
Odd/Atypical Behaviour	2.71	1.33	.761	$-.028$	$-.04$	$-.047$	$.085^{*}$
Social-Emotional Reciprocity	2.70	1.27	.872	$-.015$	$-.007$	$-.014$	.067
ASD Care-Related Stress Scale	3.12	1.51	.908	$-.074$	$-.054$	$-.077$	$.108^{*}$

* $p < .05$ (two-tailed).

** $p < .001$ (two-tailed).

Table 4
Estimates of associations with parenting stress scores derived from linear multiple regression models, showing (a) main effects and (b) effect moderation interaction terms.

(a) Main effects

		ASD Care-Related stress	
Variable (reference category)	Category (or change)	Estimate	95% CI
Parent age	(per year of age)	.07	(−.06, .20)
Education (Secondary)	Technical College	.01	(−2.40, 2.43)
	University	.40	(−1.48, 2.29)
	Other	1.71	(−.91, 4.34)
Child age	(per year of age)	−.44	(−.61, −.27)***
Restricted/Ritualized Behaviour	(per unit increase)	.39	(.25, .54)***
Communication/Language	(per unit increase)	.41	(.25, .58)***
Social-Emotional Reciprocity	(per unit increase)	.25	(.11, .40)***
Odd/Atypical Behaviour	(per unit increase)	.40	(.17, .62)***
Support (Partner)	High	−1.54	(−3.14, .06)
Support (Family)	High	−1.58	(−3.43, .28)
Support (Friends)	High	−.89	(−2.64, .86)
Support (Professionals)	High	.74	(−.90, 2.38)

(b) Effect moderations

ASD-Impact Subscales	Support moderator†	Estimate	95% CI
Restricted/Ritualized Behaviour	Partner	−.30	(−.60, −.00)*
	Family	.32	(−.03, .67)
	Friends	−.09	(−.42, .24)
	Professionals	−.05	(−.36, .25)
Communication/Language	Partner	.41	(.07, .76)*
	Family	−.26	(−.66, .13)
	Friends	.23	(−.16, .62)
	Professionals	−.19	(−.54, .15)
Social-Emotional Reciprocity	Partner	−.12	(−.43, .20)
	Family	−.10	(−.48, .28)
	Friends	−.28	(−.62, .07)
	Professionals	.11	(−.20, .43)
Odd/Atypical Behaviour	Partner	.08	(−.41, .57)
	Family	.01	(−.59, .60)
	Friends	.38	(−.16, .91)
	Professionals	.01	(−.48, .50)

Notes: CI = confidence interval; * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$; † (High vs Low).

3.2. Support and ASD symptoms/care-related stress

Table 2 presents means and standard deviations for the 13 items making up the ASD Care-Related Stress Scale, while Table 3 presents the other variables of interest utilised in this study. The two columns present means and standard deviations respectively, where mean scores have been calculated as the mean of the items for each scale, given that even within a measure the subscales may have differing numbers of items. The third column presents Cronbach alpha (α_c) scores, where all scores are greater than $\alpha_c = .7$, indicating that the scales are fit-for-purpose as they demonstrate adequate internal consistency. The right-side of Table 3 displays partial correlation coefficients between the four support categories and variables of interest. Of note is the positive association between perceived professional support and parent-rated ASD symptoms, while arguably the opposite trend is evident when considering family, friends, and partner support. However, the significant correlations are all small, indicative of weak relationships. Finally, the ASD Care-Related Stress Scale had small but significant positive relationship with the professional support category.

3.3. Moderator analysis

Hierarchical multiple linear regression modelling was employed to assess the moderating effects of the dichotomised support categories (i.e., family, friends, partner, health professionals) on the relationships between the ASD Care-Related Stress scores (the dependent variable) and the four ASD-Impact subscales (the predictor variables). Prior to the moderation analyses, partial correlation coefficients confirmed strong relationships between parenting stress and the four ASD-Impact subscales: Restricted/Ritualized Behaviour ($r = .502$, $p < .001$), Communication/Language ($r = .468$, $p < .001$), Odd/Atypical Behaviour ($r = .573$, $p < .001$), and Social-Emotional Reciprocity ($r = .532$, $p < .001$). In the first step of the moderation analysis, main effects of parent-rated ASD core symptoms on parenting stress was found for all four ASD-Impact subscales, as was also the case with child age (Table 4(a)).

Next, 16 moderator effects were estimated for each of the four support measures and each of the four ASD-Impact subscales.

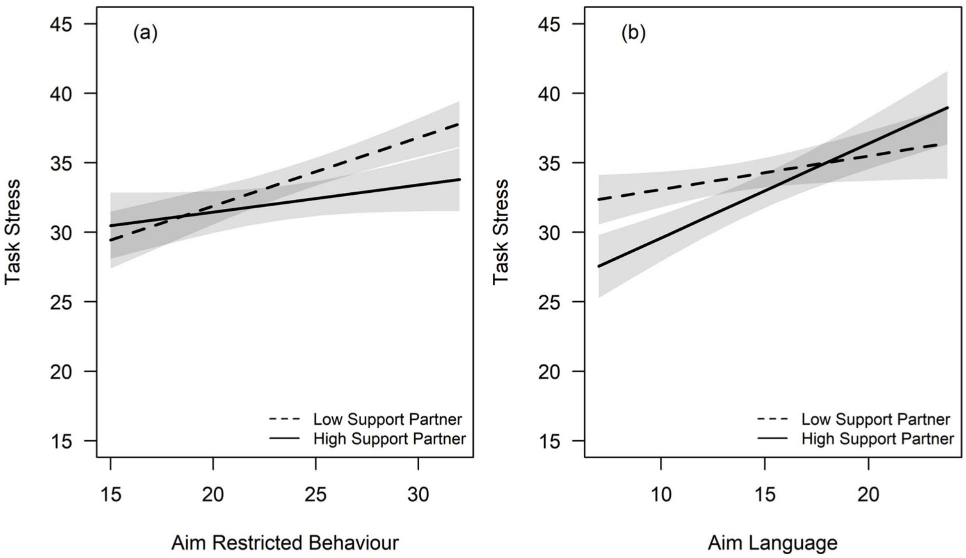

Fig. 1. Plots illustrating the interaction between partner support and two categories of ASD core symptoms on ASD-related task stress. These plots are those that exhibited statistically significant moderation effects.

Table 4(b) presents the estimated regression coefficients derived from the 16 interaction terms. Inspection of Table 4(b) shows partner support moderated the relationship between parenting stress and both the restricted/ritualized behaviour ($B = -.30$) and the Communication/Language ($B = .41$) ASD-Impact subscales. Fig. 1 presents these two significant interactions, complete with 95% confidence bands. Turning first to the relationship between restricted/ritualized behaviour and the ASD Care-Related Stress scores (Left plot, Fig. 1), stress starts at a similar level for both low and high partner support groups, but increases at a higher rate for the low support group as symptoms increase. As the regression coefficient is negative, this suggests that the greater the level of partner support, the less effect restricted/ritualized behaviours have on parental stress levels. This indicates a buffering effect of partner support. Considering the relationship between the Communication/Language subscale and ASD Care-Related Stress scores, high levels of stress are evident for those in the low partner support category regardless of symptoms. However, as symptoms increase for high partner-support group, so too does stress. Here, a positive regression coefficient indicates that as partner support increases so too does the parenting stress associated with Communication/Language deficits. With reference to Fig. 1 (Right plot), it appears that partner support may only have a buffering effect at low symptom levels.

3.4. Association between support and perceived intervention effectiveness

A battery of two-step hierarchical multiple linear regressions was undertaken to determine if there was a relationship between perceived support and parent-rated intervention effectiveness (Table 5). Here, intervention effectiveness was measured as the effect the intervention had on the child with ASD's symptoms, as-well-as whether the effect of the intervention resulted in less parenting stress. Exploratory analysis indicated no significant difference in mean support between those who were currently using an intervention with their child and those who had used one in the past. Thus engagement of an intervention (yes/no) was analysed without respect to whether the intervention was current or historical.

In terms of SLT, friends and professional support was positively associated with intervention effectiveness, though only friend support was positively associated with stress reduction. Additionally, professional support was positively associated with both the effectiveness of behavioural therapies and its impact on stress reduction. Partner and friend support were significant correlates of perceived iABA therapy effectiveness, and partner support was associated with stress relief. A positive relationship between family support and both intervention effectiveness and stress relief was found for OT. Finally, for dietary interventions, there was a negative relationship between family support and stress relief associated with engaging that intervention. As per Table 5, the additional variability in the dependent variable explained by the support categories after controlling for potential confounds (i.e., Step 1) ranged from $\Delta R^2 = .033$ (OT) to $\Delta R^2 = .307$ (iABA).

4. Discussion

4.1. Sources of support

The aim of the current study was to explore how different agencies of support modify the experience of parenting a child with ASD, in terms of the parental assessment of symptoms, and care-related stress. Consistent with existing published data (e.g., Boyd, 2002; Pepperell, Paynter, & Gilmore, 2018), we found that parents felt most supported by their partners and family than by external

Table 5
Associations between support and both perceived intervention effectiveness and stress relief. n = number of parents indicating that this intervention is currently being engaged.

	Intervention Effectiveness		Intervention Stress Relief	
	Step 1	Step 2	Step 1	Step 2
a) Speech Language Therapy (*n* = 307)				
Parent Age	.115	.124	.110	.115
Parent Education	−.082	−.048	−.117*	−.094
Child Age	−.179*	−.185*	−.181*	−.173*
Partner Support		−.077		.017
Family Support		.088		.004
Friend Support		.145*		.129*
Professional Support		.139*		.12
R^2 Change	.021	.055**	.29*	.045**
b) Behavioural Therapy (*n* = 230)				
Parent Age	−.255***		−.237**	−.231**
Parent Education	−.126*		−.110	−.083
Child Age	−.073		−.02	.004
Partner Support		.089		.116
Family Support		.127		.068
Friend Support		.041		.064
Professional Support		.14*		.143*
R^2 Change	.098***	.065**	.078***	.062**
c) iABA Therapy (*n* = 59)				
Parent Age	−.189	−.088	−.298	−.208
Parent Education	−.079	−.119	−.111	−.130
Child Age	.040	−.046	−.031	.089
Partner Support		.298*		.297*
Family Support		.234		.209
Friend Support		.279*		.118
Professional Support		−.066		.012
R^2 Change	.077	.307***	.102	.206**
d) Occupational Therapy (*n* = 302)				
Parent Age	−.149*	−.116	−.164*	−.116
Parent Education	−.073	−.066	−.023	−.004
Child Age	.058	.053	.011	−.003
Partner Support		.010		−.003
Family Support		.131*		.132*
Friend Support		.071		.101
Professional Support		.031		.067
R^2 Change	.019	.033*	.025	.047**
e) Dietary Interventions (*n* = 189)				
Parent Age	.035	.034	.033	.012
Parent Education	−.083	−.067	−.023	−.005
Child Age	−.013	−.047	−.022	−.026
Partner Support		−.134		−.068
Family Support		−.155		−.227**
Friend Support		.161		.109
Professional Support		−.068		.055
R^2 Change	.007	.057	.001	.051*

* $p < .05$.
** $p < .01$.
*** $p < .001$.

sources of support such as friends and health professionals. Further, no significant difference between friend and professional-related support was noted, indicating that a divide between internal (within family) (i.e., partner and family) and external (i.e., friends and professionals) may exist. Partners, rated as the highest source of support, may reflect a ‘proximity’ effect whereby they are typically close by or easily accessible through technology (e.g., cell phones), and what is more, have an obligation to assist, particularly in their parental roles.

In relation to friends this lack of perceived support may be the result of a range of factors, including parents not wanting to burden their friends and potentially lose friendships, their sense that friends avoided them because of their challenging child, and stigma or lack of understanding of the nature and challenges of ASD (Ooi, Ong, Jacob, & Khan, 2016). Indeed, Pepperell et al. (2018) report that in their study, one of the most important characteristics of social support was significant others’ understanding of the difficulty of raising a child with ASD, and that parents tend to seek support from other parents of children with disabilities (Boyd, 2002).

In relation to professionals, it is possible that they were not considered a primary source of support because of limited access and infrequency of contact. Indeed, Marsack and Samuel (2017) have suggested that attention may need to be directed as to the types and costs of professional services available. However, Samuel, Hobden, LeRoy, and Lacey (2012) also argue that on a day-to-day basis, parents need more informal, rather than formal support. It is possible that support groups, which sit somewhere between informal and formal sources of support, may be useful in terms of providing both emotional and informational support (Ooi et al., 2016) and this could be explored further.

Child and parent ages were negatively correlated with perceived family and partner support, and while the age of the child has previously been found to have some impact on levels of subjective burden, the results have been mixed (McStay et al., 2014; Tehee et al., 2009). Considering family support, it may be that family members feel they have contributed enough over time and, with reference to the chronic nature of ASD, either don't want to be involved or are fatigued of being involved across long time periods. Alternatively, as the adaptive coping skills of parents tend to increase over time (Gray, 2003), and as children with ASD possibly tend to exhibit improvements as they grow (Shattuck et al., 2007), it may be the case that family perceive there to be a decreased need for support and become less available.

When interpreting the decrease in perceived partner support, the gender disparity in the sample (91% female) is important to consider. As for families in general, fathers may be more actively involved in the early years, and as reported by Pepperell et al. (2018), traditional gender-based care roles may mean that mothers shoulder more of the parenting burden. Ooi et al.'s (2016) review likewise suggests that mothers often deal with the strain of caring themselves. The perceived lack of ongoing partner support is of concern, and may explain research that reports that mothers of older children with ASD tend to have higher exhaustion levels or maladaptive emotions than mothers of younger children with ASD (Gray & Holden, 1992; Smith et al., 2008; Tomanik, Harris, & Hawkins, 2004), and may experience more stress and mental health issues than fathers (Gray, 2003; Tehee et al., 2009), although research also suggests that fathers are more stressed than the general population (Jones, Totsika, Hastings, & Petalas, 2013). Indeed, it is important to remember that partners may themselves be struggling with the demands of parenting and may thus be unable to assume a primary support function (Coyne, Ellard, & Smith, 1990). However, the perceived lack of partner support may be one of the reasons why divorce rates are typically higher in families with an ASD child (Ooi et al., 2016). As reported by Marsack and Samuel (2017), caregiver burden may increase over time and affect quality of life in many ways. It is thus imperative that parents have access to a social support network to help manage some of the challenges associated with providing care across the lifespan.

4.2. Support, stress and ASD symptoms

Perceived support from informal sources did not appear to influence how parents assess their child's ASD-related symptoms. It could be hypothesised that parents perceiving themselves to be receiving higher levels of support would tend to struggle less, and consequently rate their child's symptoms as less severe than a comparable parent-child dyad with lower levels of perceived support. However, it is also possible that greater symptom severity might be expected to be associated with parents' need for increased support. Furthermore, the support which parents receive from informal sources may be more emotional, rather than instrumental, in nature, and thus explain why ratings of ASD-related symptoms are not affected. For example, Ooi et al. (2016) suggest that it may not only be the practical support that parents value, but rather that mothers valued support in helping them cope with the label of autism.

However, while no relationships of substance were found between perceived support and child symptoms, a small but significant negative correlation was uncovered between perceived professional support and both ASD Care-related Stress scores and ASD symptoms, albeit weak. Here the suggestion is that as professional support increases, the daily stressors associated with the care of an ASD child decrease. This may be because of the nature of support provided by professional sources, which may be more directly targeted towards helping parents with symptom management than the support provided by informal sources. Professionals may also be more able to interact appropriately with the child (Ooi et al., 2016). On the other hand, it may also be that professionals, who are familiar with and understand the nature of children with ASD and the challenges this presents for parents, may offer some of the emotional support that parents need. Ooi et al.'s (2016) review suggests that parents value professionals' ability to be compassionate and sensitive in their support. Note however that when support was dichotomised into low and high levels in our study, the link between professional support and stress scores was no longer significant.

While individual resilience or the deployment of adaptive coping strategies allow parents to adjust with the challenges faced with caring for a child with ASD, both can be enhanced by the provision of external support (Ooi et al., 2016). Typically there is a positive association between ASD core symptoms and parenting stress (e.g., Shepherd, Landon, Goedeke, 2018), and this relationship would likely be moderated by perceived support. In our study, we found that partner support was associated with decreased stress, moderating the relationships between two ASD core symptoms and parenting stress. First, partner support moderated the relationship between Restricted/Ritualized Behaviour and ASD Care-related Stress scores, providing evidence of buffering. Here, high levels of perceived support from one's partner was associated with less care-related stress as symptom severity increased. Second, the relationship between Communication/Language impairment and ASD Care-related Stress scores was also moderated by partner support. For this case those rating their partner's support as high reported less care-related stress at lower symptom levels compared to the low support group, but for high symptom levels the two groups were comparable.

We explored the relationship between parents' assessment of the support they received and the perceived effectiveness of and stress relief provided by five different intervention types. In the ASD context it is reasonable to assume that the more support a parent receives, the better their child's outcomes will be, as typically parents are heavily involved in their child's interventions (Karst & Van Hecke, 2012). We found that support is related to both perceived intervention effectiveness as well as stress relief, though the pattern differs across intervention modality. For speech therapy, parental perceptions of intervention effectiveness were positively correlated with perceived friend and professional support, but for behavioural therapy this was only true only of professional support. For the more intensive form of behavioural intervention, iABA therapy, partner and friend support were both positively associated with intervention outcome. Finally, family support was positively associated with Occupational Therapy outcomes. The same trend of different forms of support being significant for different intervention modalities also held when looking at the relationship between perceived support and the degree to which the intervention relieved care-related stress.

The question as to how these agencies of support increase perceived intervention effectiveness cannot be answered by our data and is a question for future research. Specifically, is professional support more instrumental (or *tangible*) in nature while support from friends and family more emotional (e.g., empathy and/or encouragement), helping to reduce experiences of psychological distress? Additionally, it is unlikely that the support offered from a particular agency serves a single function, for example, to various degrees a partner might offer instrumental, emotional, and companionship support, while a health professional might contribute instrumental, emotional, and informational support. Developing a better understanding of factors related to outcomes is important both to facilitate support strategies for families themselves, as well as to support outcomes for children.

4.3. Limitations/future directions

Results of this study should be interpreted with reference to the inherent limitations of the design. First, all relationships reported in the study are likely to be bidirectional, and so inferences of cause-and-effect cannot be made. Second, we measured perceived and not actual (i.e., enacted) support, and so the findings cannot be taken to represent the real, objective, support people receive. Support sources may also include support groups, use of which was not assessed in this study. Third, we assessed levels of perceived support, without differentiating the function of the support i.e. whether the support was emotional, informational or instrumental. Fourth, adapting only one of two subscales from the shortened version of the 82 item AIM scale may bias our measures of ASD core symptoms in an undetermined way, and means that potentially interesting relationships between key variables and the frequency of core symptoms (Mazurek et al., 2018) could not be examined. Importantly, our use of the abbreviated descriptors published in Kanne et al.'s (2014) paper limits direct comparisons between our subscale means with those reported in other studies, though the high Cronbach's coefficients obtained in the current study indicates that the abbreviated descriptors did not invalidate our results. Fifth, while some studies have validated parent-ratings of child symptoms (e.g., Miller, Perkins, Dai, & Fein, 2017), subjective factors such as parent mental health and parenting stress may serve to bias these ratings. In addition, we utilised an Australian-developed ASD care-related stress scale and our sample came from a single country (New Zealand), with unique cultural factors, for example, attitudes towards help-seeking, which may limit the generalizability of our findings.

The use of psychometric scales to measure complex psychological constructs is always fraught and operationalising variables to address specific hypotheses can result in the negligence of other equally important constructs, or the adoption of pre-existing scales that are only partially suitable. The focus of the current study was ASD, and so child ASD symptoms were obtained via parental ratings. The use of parent ratings has been questioned, even though the assessment capabilities of parents may be somewhat underestimated (Sacrey et al., 2018). Future research however, could develop more parent-friendly scales that allow direct comparison with clinical measures. A more serious problem is the issue of disentangling the effects of ASD core symptoms on stress from problem behaviours associated with comorbidities such as anxiety and ADHD. Additional clinical research is required to determine how independent (or not) problem behaviours such as aggression and defiance interact with ASD core symptoms, and whether their effects on parenting stress are additive or not. As such, the AIM scale focused on core symptoms and not problem behaviours, and so this can be considered an additional limitation of the research. Additionally, the operationalisation of parenting stress can be difficult, given that general measures may not capture the true impact of ASD-related stressors as effectively as ASD-specific measures (Shepherd, Landon, Taylor & Goedeke, 2018). Currently, there is no ASD-specific measure specifically developed for measuring parenting stress in those whose children are of school age, and the development of such a scale would be beneficial. Finally, future research into parental stress and support could include measures that tap deeper into child cognitive function, as intellectual ability has been shown to covary with parenting stress, albeit not in a linear fashion (Rao & Beidel, 2009).

4.4. Conclusion/implications

Parenting a child with ASD may be challenging, and while parents tend to call largely on the informal support sources of family to assist them, this support tends to diminish over time and does not necessarily reduce care-related stress. Parents did not perceive friendships to be a significant source of support. This highlights the potential need for education of significant others in parents' lives around ASD challenges and how best to provide support on an ongoing basis. While parents may tend to rely on family support, the support from professionals may help to reduce care-related stress. Support from both formal and informal sources may also be related to treatment effectiveness and perceived stress levels. However, it is important to explore the role of support further, by examining not only the sources of support available to parents and the effect of this support, but what function the support provided by each serves and how this relates to a range of variables, including general stress levels and mental health. It is possible that parents rely on different sources of support for different types of support, and that these may be differentially related to outcomes. Finally, it is important to recognise that the diversity of the ASD population and challenges these present for parents may also create difficulty in providing effective support for families caring for children with autism (Fayerberg, 2011).

Conflict of interest

The authors declare that there are no conflicts of interest.

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