

Symptom severity, caregiver stress and intervention helpfulness assessed using ratings from parents caring for a child with autism

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Abstract

This exploratory study assessed the relationships between autism spectrum disorder symptoms, caregiver stress and intervention helpfulness, using parent ($n = 182$) ratings. Advocacy and intervention-related tasks were rated more stressful than support tasks (e.g. toileting, mealtimes), indicating that advocacy is emerging as a major caregiver task for parents. Deficits in prosocial behaviours were perceived to have the highest impact on the child's function. No difference was found between mean helpfulness ratings across the six representative interventions taken from the New Zealand context. Differences in care-related task stress across intervention choices were better explained by differences in symptom severity, suggesting that impairment drives intervention choice. Limited evidence was uncovered suggesting that intervention helpfulness moderates the relationship between core autism spectrum disorder symptoms and parent stress.

Keywords

autism spectrum disorders, interventions, parents, task stress

Autism is characterised across a spectrum, varying in both symptom presentation and severity. The *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; DSM-5) combines autistic disorder, Asperger's disorder and pervasive developmental disorder not otherwise specified (PDD-NOS) into the broad diagnostic category of autism spectrum disorder (ASD). Additionally, comorbidity is common, with upwards of 70% of individuals with ASD diagnosed with concurrent medical, developmental or psychiatric conditions (Lai and Oei, 2014). Estimating the prevalence of ASD is difficult (Mandell and Lecavalier, 2014), and while there is some evidence that cases of ASD are increasing (Hansen et al., 2015; King and Bearman, 2009; Lord and Bishop, 2010), other data suggest that the percentage of children with ASD may be stabilising (Christensen et al., 2016). In the United States, it was estimated that 1 in 68 children aged 8 years met the criteria for ASD in 2012 (Christensen et al., 2016). In Australia, the prevalence rate is approximately 1/120 (Barbaro and Dissanayake, 2010), while in New Zealand, it is estimated that more than 40,000 people meet the diagnostic criteria for ASD (Ministries of Health and Education, 2008).

Individuals diagnosed with ASD exhibit a wide range of abilities and difficulties (Howlin, 2006). This diversity creates challenges in the provision of effective support for

parents caring for children with ASD, and in part explains why these parents are vulnerable to stress and depression (Benson and Karlof, 2009). Parents of children with ASD experience higher levels of stress, depression and anger than other parents (e.g. Duarte et al., 2005; Hoffman et al., 2009; Ingersoll et al., 2011; Ingersoll and Hambrick, 2011; Lutz et al., 2012; Rao and Beidel, 2009), including parents of children with other developmental disabilities (e.g. Estes et al., 2009; Schieve et al., 2011). Pertinently, chronic stress, worry and exhaustion often leave parents in need of therapy themselves (Rivard et al., 2014), and alarmingly such stress can counteract the positive outcomes of intervention for young ASD children (Osborne et al., 2008). Intensive time and financial commitments to intervention regimes may also compound stress caused by ASD-related problem behaviours such as hyperactivity, irritability, anti-social behaviour and the inability to complete simple self-care behaviour. It comes as no surprise then that parents

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report greater compliance to less demanding interventions (Moore and Symons, 2009).

Parental stress is predicted by both the child's (the so-called 'wear-and-tear' concept) and parent's ages. However, considering all child and parental characteristics, symptom severity appears to be the strongest predictor of caregiver stress (Lecavalier et al., 2006), though not always (Falk et al., 2014; Minnes et al., 2015), and the relationship may not necessarily be linear (Rao and Beidel, 2009). Interestingly, two core deficits associated with ASD, language/communication difficulties and stereotyped behaviours, seem not to contribute significantly to caregiver stress (Davis and Carter, 2008; Lecavalier et al., 2006; Tomanik et al., 2004). Instead, conduct problems and a lack of prosocial behaviours emerge as better predictors (Huang et al., 2014; Karst and Van Hecke, 2012). For ASD, the demands of caring and time requirements are substantial, often more so than those for other developmental disorders (Plant and Sanders, 2007; Schieve et al., 2011). Greater symptom severity negatively impacts self-care behaviour and other daily living skills, which leaves the responsibility of simple caregiving tasks – such as bathing, toileting, dressing or eating – to parents. Difficulty of caregiving tasks and levels of parental stress have been shown to correlate highly (Plant and Sanders, 2007).

Furthermore, differences may exist in the way the two genders respond when caring for a child with ASD (Falk et al., 2014), though findings are tentative, as studies tend to fail in their efforts to recruit fathers (e.g. Mulligan et al., 2012; Plant and Sanders, 2007). Research suggests that while anxiety, depression and high stress levels are reported in both parents of children with ASD (Fayerberg, 2011), mothers may experience higher stress levels (Gray, 2003; Tehee et al., 2009). However, Rivard et al. (2014) point out that larger and more equivalent mother–father participant numbers are associated with reports of greater father parenting stress. Where greater stress levels are reported for mothers (e.g. Falk et al., 2014), Hastings et al. (2005) suggest that this is caused by the women's traditionally greater caregiving activities, and that this also explains the finding that maternal stress was more strongly associated with child behaviour problems. Whereas Pozo et al. (2014) reported a link between the severity of the disorder and behaviour problems for both mother and fathers, Rivard et al. (2014) suggest that paternal stress may be mediated more by their wives or partners' experiences of depression, rather than their child's symptoms per se.

Currently there is no cure for ASD, and the burden of care has traditionally been placed on parents. A range of interventions is available for those with ASD, with varying degrees of evidence as to their efficacy. However, the extent to which interventions are government funded, and are therefore universally accessible, varies across jurisdictions. Furthermore, the efficacy of available interventions

has yet to be sufficiently evaluated (Odom et al., 2010), with small samples sizes and disagreement over appropriate outcome measures being salient limitations in reported studies (Karst and Van Hecke, 2012). Nonetheless, parents of children with ASD typically access several different interventions, with some reports indicating an average of seven different approaches being engaged at one time (Mackintosh et al., 2012), with accompanying time and financial strains. Beyond the costs, parental involvement in interventions is generally mandatory (Schertz et al., 2011), with the majority of interventions involving the 'parent as a therapist' to a degree (e.g. Granger et al., 2012). However, while the involvement of parents in their child's intervention appears important and beneficial, risks also exist, including burnout and unmet expectations, all which may become counterproductive in terms of their child's development and well-being (Falk et al., 2014).

In New Zealand, the mainstay of ASD intervention is the Ministry of Education Early Intervention Service, a government-funded free service provided to families identified as having a child with special needs. The service is eclectic, providing elements of several evidence-based interventions delivered by a range of professionals in conjunction with family in the child's home, or with early childhood educators and speech language therapists in educational settings. Regional health services may also provide occupational therapists, who focus on developing the child's ability to participate in regular daily activities (see Bagatell and Mason, 2015, for a review). Other interventions are available to parents and their children, however these are largely at the family's expense, and thus accessibility can be restricted. Early and intensive applied behaviour analysis (ABA) interventions are available and are better supported by evidence (Klintwall et al., 2015). Less intensive behavioural therapy (BT) is an option for those unable to bear the financial or time burden of the intensive ABA approach. Private speech language therapists can be engaged to assist with language-based difficulties or requested through the Ministry of Education. Finally, although generally eschewed by the medical establishment, dietary interventions are available either under guidance of qualified health professionals, unregulated specialists or as self-directed by the parent. Note that medical treatments for ASD are not common in New Zealand, likely due to the lack of clinical evidence (McPheeters et al., 2011), and may explain the low helpfulness ratings that general practitioners receive in this country (Searing et al., 2015).

The interventions parents choose for their child with ASD are influenced by a multitude of factors, and parents may engage numerous interventions simultaneously (Mackintosh et al., 2012). This fact in itself makes the evaluation of intervention efficacy challenging. Intervention choice may be driven by parental perceptions of core ASD symptoms (Shyu et al., 2010), ease of implementation even

when not supported by evidence (Lord and Bishop, 2010) and cultural beliefs (Karst and Van Hecke, 2012). Cost is another key factor, as treatment costs can increase the cost of raising a child with ASD three-times above that of a typically developing child (Sawyer et al., 2010). Furthermore, parents report career restrictions due to their caregiving responsibilities (Montes and Halterman, 2008; Vohra et al., 2014), and access to government-funded interventions varies both internationally and within countries. In New Zealand, securing appropriate access to government-run services may require substantial patience and persistence (Searing et al., 2015), and thus the role of the parent as child advocate becomes an additional caregiving task that can contribute to stress (Plant and Sanders, 2007) and fatigue.

The efficacy of an intervention (or ‘formal support’) can be estimated using randomised control designs and comparing key outcome measures between those receiving the intervention and those receiving the ‘placebo’. A complementary approach is to consider intervention *effectiveness* by soliciting parental ratings of how helpful the interventions have been in relation to their child and themselves. Such parental data are important, as quality of care is dependent upon the quality of the family environment. Yet, how ASD interventions impact parents and families is rarely addressed (Karst and Van Hecke, 2012), which is concerning given the transactional effects of the family environment. Indeed, interventions that reduce ASD symptoms may not necessarily reduce caregiver stress, and parental perceptions of the helpfulness of an intervention is a better predictor of parent health-related outcome measures than the objective characteristics (e.g. duration, type) of the intervention itself (Brown et al., 2010). On this basis, some make the argument that the helpfulness of existing resources and interventions should be evaluated using parental self-report scales (Karst and Van Hecke, 2012; Searing et al., 2015).

Parental data also offer a different perspective from that gleaned from clinical outcome measures (Grindle et al., 2008), though existent literature largely neglects parent assessments of themselves and their ASD child. This study adapts previous studies in the area by adopting a parent-focused, as opposed to a clinically focused, approach, and in doing so explores relationships between key ASD care-related measures through a different lens. Due to a lack of data acquired directly from parents, this study is largely exploratory, though with reference to findings reported by studies involving formal clinical assessments of parents and their children, a number of hypotheses can be formulated. First, a positive relationship between perceived symptom severity and care-related task stress would be expected, consistent with the literature (e.g. Bebko et al., 1987). Second, assuming symptom severity drives the number of interventions engaged (Shyu et al., 2010), we predict a positive relationship with parent-rated ASD child

symptom severity and the total number of interventions engaged. Allied to this, the greater the number of interventions engaged, the more parents will report caregiver stress. Third, Plant and Sanders (2007) reported that professional support moderated the relationship between child symptom severity and caregiving stress, though did not specifically declare that such support included child interventions. Additionally, then, we hypothesise that perceived helpfulness of an intervention will moderate this relationship.

Method

Participants

The participants were 22 males and 162 females with a mean age of 43.71 years (standard deviation (*SD*) = 8.45, Min = 24, Max = 55), who had been caring for sons ($n = 155$) or daughters ($n = 28$) with ASD for an average of 10.52 years ($SD = 5.29$, Min = 1.2, Max = 33). The mean age of the children was 11.22 years ($SD = 4.78$, Min = 2.1, Max = 20) with mean onset of ASD symptoms being 1.95 years ($SD = 1.48$). Parents were asked to indicate if their child had received a formal medical diagnosis and if so from whom. Only those indicating a diagnosis from a qualified medical or health professional were included in the study. Further demographic details of the sample are provided in Table 1. Ethics approval was given by the Auckland University of Technology’s Human Ethics Committee (AUTEK: 13/105).

Measures

A questionnaire probing demographic information, severity of children’s autism-related symptoms, perceived helpfulness of interventions and perceived caregiver task stress, was presented online.

ASD symptom severity. Severity of children’s ASD symptoms was measured using the ‘impact’ dimension of the Autism Impact Measure (AIM), developed by Kanne et al. (2014). A total of 25 parent-rated items probing the impact of ASD symptoms on their child’s daily functioning (with reference to the previous fortnight), were presented. The AIM uses a 5-point Likert-scale ranging from 1 (*Not at All*) to 5 (*Severely*) and measures both the presence of maladaptive behaviours (e.g. ‘engaged in rituals or routines’) and the absence of skills (e.g. ‘used gestures’). The AIM has four subscales: Restricted/Ritualized Behaviours, Odd/Atypical Behaviours, Communication/Language Impairment, and Social-Emotional Reciprocity deficits.

Helpfulness of interventions. To obtain a profile of the interventions that had been implemented, past or present, participants indicated if one or more of six interventions had been engaged. The six interventions are representative of the

Table 1. Demographic profile of the sample.

Category	n (%)
Gender of participant	
Female	162 (88)
Male	12 (6.5)
Gender of individual with ASD	
Female	28 (15.30)
Male	155 (84.70)
Parent's level of education	
Secondary school	43 (23.50)
Tertiary college	32 (17.50)
University	81 (44.30)
Other	27 (14.80)
Sole caregivers	
Yes	128 (69.90)
No	55 (30.10)
Interventions accessed	
Applied behaviour analysis (ABA)	47 (25.8)
Behavioural therapy (BT)	95 (52.2)
Dietary interventions	75 (41.2)
MoE early intervention	114 (62.6)
Occupational therapy (OT)	106 (58.2)
Speech language therapy (SLT)	129 (70.9)
Total number of interventions accessed	
None	18 (9.9)
One	18 (9.9)
Two	26 (14.3)
Three	45 (24.7)
Four	32 (17.6)
Five	25 (13.7)
Six	18 (9.9)

ASD: autism spectrum disorder.

most common ASD treatments accessed in New Zealand, and comprised BT, early and intensive ABA therapy, dietary interventions (Dietary), Ministry of Education (MoE) Early Intervention Services, occupational therapy (OT) and speech language therapy (SLT). Table 2 provides a brief description of each of these therapies as applied in the New Zealand context. Those interventions that had been tried were then rated on a 7-point Likert-type scale ranging from 1 (*Not at all helpful*) to 7 (*Very Helpful*). Thus, for each intervention a binary variable was obtained indicating whether the participant's child had utilised the intervention (coded Yes/No) and, for those responding 'Yes', a rating of the overall helpfulness of the intervention.

Caregiver task stress. Caregiver task stress was measured using a subset of a 22-item checklist originally developed by Plant and Sanders (2007). From the original 22 items, a 13-item checklist was compiled (see Table 3) by selecting the Top 10 most stressful tasks for both men and women (where seven of the items overlapped). Participants rated their stress levels when conducting caregiving tasks using

Table 2. Definitions of common New Zealand ASD interventions as defined to the participants.

Intervention	Description
Behavioural therapy	Behavioural therapy is the management and/or modification of behaviour using reinforcement techniques to help increase desired behaviours and decrease undesired behaviours. Note: this is not the same as intensive applied behaviour analysis.
Applied behaviour analysis (ABA) therapy	This approach is also known as the Lovaas Model of Applied Behaviour Analysis and is characterised by an intensive programme of behavioural analytic procedures delivered by trained professionals for up to 40 h/week.
Dietary interventions	Dietary interventions refer to choosing foods to add or remove from your child's diet to improve general health and well-being and are guided by a trained health professional. A common dietary choice is gluten-free/casein-free diet.
Ministry of Education (MoE) Early Intervention Services	The government's early intervention service provides specialist support to help parents gain the confidence, knowledge and skills to support a child's learning and development.
Occupational therapy (OT)	Occupational therapy involves trained therapists assisting children and their caregivers to build skills that enable them to participate in meaningful activities as independently and satisfactorily as possible. These activities may include toileting, feeding, playing and school-related skills.
Speech language therapy (SLT)	Speech language therapy is when a trained therapist works with individuals to help them develop their language, communication and interpersonal skills using a range of established techniques.

ASD: autism spectrum disorder.

a 7 point Likert-scale ranging from 1 (*Not at all Stressful*) to 7 (*Very Stressful*). A 'not applicable' option was also available for tasks that were not performed by the parent. The 13 scores were then averaged to provide a mean total score, with higher scores indicating greater stress.

Procedures

Invitations to participate in the study were sent to parents caring for an individual with ASD through e-mails with the help of autism support agencies located in New Zealand.

Table 3. Means (*M*) and standard deviations (*SD*) of the 13 items making up the caregiver task stress scale.

Item	<i>M</i>	<i>SD</i>
Advocating on behalf of him or her	4.87	2.07
Attending medical/therapy appointments	3.55	2.29
Cleaning up after him or her	3.54	2.18
Doing therapy/educational activities	3.35	2.49
Helping and supervising at mealtimes	3.34	2.02
Transporting to appointments	3.26	2.12
Settling him or her at bedtime	3.22	2.42
Filling out forms relating to him or her	2.97	1.98
Getting him or her ready for bed	2.68	2.25
Helping and supervising with toileting	2.62	2.36
Giving medication to him or her	2.41	2.32
Helping and supervising with dressing	2.39	2.07
Helping and supervising with bath time	2.34	2.05

Higher scores indicate greater stress, and means are ranked from highest to lowest.

The invitations provided the parents with a link to the online questionnaire. A Participant Information Sheet was attached to the email invitation and also downloadable from the online questionnaire site. Respondents were informed that participation was voluntary and anonymous, and that ethical approval had been sought and granted by the University's Ethics Committee. The duration of the data collection period was 40 days.

Statistical analysis

All statistical analyses were performed using the Statistical Package for the Social Sciences (v.22). For all tests, the significance level was set at $\alpha = 0.05$. Descriptive statistics were calculated to profile the demographic characteristics of the sample, and measures of central tendency and dispersion for the AIM scale, caregiver task stress, and helpfulness of interventions were also calculated. Internal consistency statistics (Cronbach's alpha: α_c) were calculated for the AIM scale, given its relatively recent introduction. Preliminary analysis indicated no effect of parent education and gender, and child gender upon the various relationships of interest, and so scrutiny of these variables was not pursued in the analysis. Zero and first order correlation coefficients (controlling for parents' and child's age) were calculated to investigate the associations between key variables. When comparing mean helpfulness ratings across the six intervention types, a conservative between-groups one-way analysis of variance (ANOVA) was conducted, even though the groups were not strictly independent. Where appropriate, bivariate analyses of means consisted analysis of covariance (ANCOVA) and multiple analysis of variance (MANOVA), and the AIM subscales summed and selectively used as a covariate. Finally, hierarchical regression analyses were used to

assess the moderating effects of intervention helpfulness on the relationship between the AIM subscales and caregiver task stress.

Results

Exploratory analyses

Caregiver task stress. Mean scores for the caregiver task stress scale items are displayed in Table 3, ranked from most-to-least stressful, with this scale exhibiting satisfactory internal consistency (Cronbach's alpha of 0.908). A battery of one-sample *t*-tests indicated that all 13 mean scores are significantly greater than one ($p < 0.001$), the scale value corresponding to 'Not at all Stressful', which indicates that the selected tasks were on average all considered stressful, albeit to varying degrees. The item mean for the caregiver task stress score was 3.8 ($SD = 1.41$), while the mean for the total score was 40.61 ($SD = 19.74$).

Perceived helpfulness of interventions. Table 1 shows the percentages of participants indicating that their child had, at some point in time, engaged with each of the six interventions. In this sample, SLT was the most accessed intervention (71%) and ABA therapy the least (26%). The total number of interventions engaged is likewise presented in Table 1, with the median score being three unique interventions. Mean helpfulness ratings are indicated in Figure 1, with ABA receiving the highest mean rating ($M = 4.28$, $SD = 2.29$) and dietary interventions the lowest ($M = 3.57$, $SD = 2.26$). A one-way ANOVA comparing mean helpfulness ratings across the six interventions failed to reach significance ($F(5,560) = 1.73$, $p = 0.126$).

Relationships between caregiver task stress and intervention choices. One-way ANCOVA was used to explore the impact of intervention choice on caregiver task stress. Both parental and child ages were included as covariates. After confirming assumptions, using Shapiro-Wilk and Levene's tests, six ANCOVA's were performed, one for each intervention type. Mean caregiver task stress scores as a function of intervention choice (i.e. yes or no) are displayed in Figure 2. The ANCOVA indicated that intervention choice was not significantly related to caregiver task stress for the ABA, BT or dietary approaches ($p > 0.05$). However, mean caregiver task stress for parents who exposed their children to MoE ($F(3,146) = 8.01$, $p = 0.005$, partial $\eta^2 = 0.052$), OT ($F(3,146) = 19.39$, $p < 0.001$, partial $\eta^2 = 0.12$) and SLT ($F(3,146) = 15.14$, $p < 0.001$, partial $\eta^2 = 0.10$) interventions was significantly higher than those who had not. However, the proportion of variance in caregiver task stress accounted for by intervention choice was low, ranging between 5.2% and 12%. Furthermore, statistical significance was eliminated when the AIM total score was included as an additional covariate ($p > 0.05$).

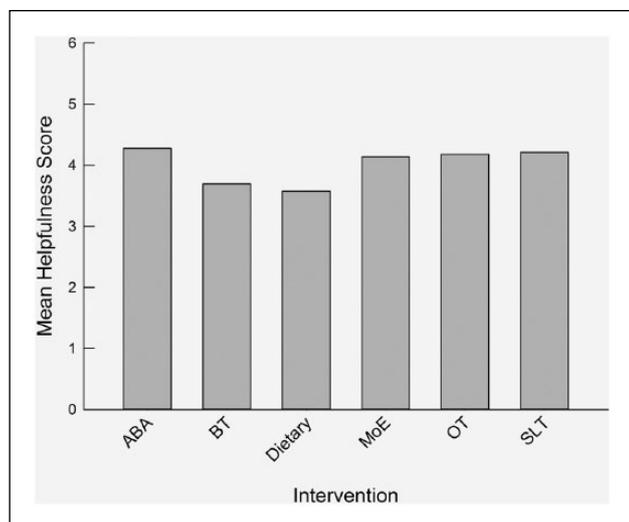


Figure 1. Parent-rated mean helpfulness scores for six types of ASD intervention.

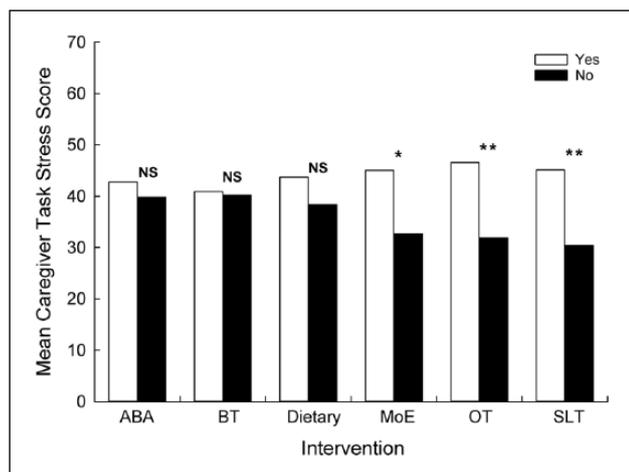


Figure 2. Caregiver task stress as a function of intervention choice (Yes/NO). Asterisks (* $p < 0.05$, ** $p < 0.001$) indicate significant differences between the means of the Yes and No groups.

Relationships between AIM subscales and intervention choice.

To explore the effect of intervention choice on parent-reported ASD symptoms, a total of six 2 (intervention yes or no) by 4 (AIM subscales) multivariate analysis of covariances (MANCOVAs) were performed, with parent and child age as covariates. Bartlett’s test of sphericity and Box’s M statistics confirmed that the data satisfied homogeneity of covariance assumptions. Table 4 presents mean scores for each of the four AIM subscales (columns) grouped by ‘yes’ or ‘no’ responses to the six interventions (rows). The final column of Table 4 presents Wilks Lambda statistics (λ), with significant multivariate effects noted for the MoE ($F(4,141) = 4.45, p < 0.001, \eta^2 = 0.11$), OT ($F(4,141) = 4.71, p < 0.001, \eta^2 = 0.12$) and SLT ($F(4,141) = 7.44, p < 0.001, \eta^2 = 0.18$) interventions. With reference to Table 4, the MoE intervention had a significant effect on the language subscale, while both OT and SLT interventions had significant effects on all but the Odd/Atypical Behaviour subscale. For all significant results, the mean AIM score for intervention engaged (i.e. Yes) was higher than the intervention not engaged (i.e. No) group, indicating that children exposed to these three interventions were rated by their parents as more symptomatic than children whose parents had not chosen these interventions. With reference to Cohen (1988), the effect of intervention choice on caregiver task stress can be considered medium (MoE and OT) and large (SLT).

The relationship between perceived symptom severity and care-related task stress.

Our first hypothesis posited a positive relationship between perceived symptom severity and care-related task stress. The four AIM subscale means and standard deviations are presented in Table 5, along with Cronbach’s alphas ($\alpha_c > 0.70$). Taking into account the different number of items across the subscales, parents reported that the Social-Emotional Reciprocity subscale has the highest impact on the child’s daily functioning, and the Odd/Atypical Behaviour subscale the least. A repeated-measures ANOVA indicated that significant differences

Table 4. Mean AIM subscale scores sorted by intervention engagement (Yes/No).

Intervention	Restricted/Ritualized Behaviour		Language/Communication		Social-Emotional Reciprocity		Odd/Atypical Behaviour		MANOVA
	Yes	No	Yes	No	Yes	No	Yes	No	
ABA	24.9	23.1	15.58	13.79	19.15	18.92	13.6	13.58	$\lambda = 0.964$
BT	24.67	23.6	14.75	13.7	19.06	18.89	14.02	13.07	$\lambda = 0.970$
Dietary	25.17	23.45	14.56	14.1	18.95	19	13.51	13.64	$\lambda = 0.976$
MoE	25.06	22.53	15.6	11.79*	19.29	18.41	13.64	13.47	$\lambda = 0.888^*$
OT	25.42	22.17*	15.57	12.17**	20.09	17.21*	13.8	13.24	$\lambda = 0.882^*$
SLT	25.111	21.81*	15.72	10.6**	19.74	17.07*	13.82	12.98	$\lambda = 0.796^{**}$

AIM: Autism Impact Measure; MANOVA: multiple analysis of variance; ABA: applied behaviour analysis; BT: behavioural therapy; MoE: Ministry of Education; OT: occupational therapy; SLT: speech language therapy.

** $p < 0.001$, * $p < 0.05$.

Table 5. Zero order (left of the major diagonal) and first order (right of major diagonal) correlation coefficients for the four AIM subscales and the caregiver task stress scale.

Scale	1	2	3	4	5
1. Restricted/Ritualized Behaviour	0.820	0.525**	0.625**	0.493**	0.572**
2. Communication/Language	0.440**	0.858	0.659**	0.477**	0.538**
3 Social-Emotional Reciprocity	0.611**	0.657**	0.761	0.581**	0.532**
4. Odd/Atypical Behaviour	0.481**	0.483**	0.585**	0.872	0.511**
5. Caregiver task stress	0.560**	0.560**	0.522**	0.494**	0.908
Number of items	8	5	7	5	13
Mean	23.78	14.31	18.94	13.57	40.61
SD	6.82	5.93	5.99	5.19	19.74
Item mean	2.97	2.86	2.71	2.71	3.12

AIM: Autism Impact Measure.

First order correlations control for parent and child ages. Means, standard deviations (SD) and Cronbach's alpha (major diagonal in bold font) are also given.

** $p < 0.001$.

existed across the four subscales ($F(3,450) = 7.01, p < 0.001$), and *post hoc* tests revealed that all pairwise comparisons across the four AIM subscales were significant ($p < 0.001$). As presented in Table 5, after controlling for parent and child ages, there were strong positive correlations ($r = 0.511$ to $r = 0.572$) between the caregiver task stress scale and the four AIM subscales, lending support to the first hypothesis that as parent-rated ASD symptom severity increases so too does their reported stress.

Relationship between intervention number and ASD symptoms severity/caregiving stress. The study's second hypothesis sought evidence of a positive relationship between both parent-rated ASD child symptom severity and caregiver stress, and the total number of interventions engaged. Figure 3 plots mean scale scores for the four AIM subscales and the caregiver stress scale as a function of number of interventions. Spearman's Rho (r_s) correlation coefficients were derived to examine the behaviour of the five functions across number of interventions. Small-to-moderate significant positive correlations were found between number of interventions and caregiver task stress ($r_s = 0.276, p < 0.001$), Restricted/Ritualized Behaviours ($r_s = 0.225, p < 0.001$), Communication/Language ($r_s = 0.339, p < 0.001$) and Social-Emotional Reciprocity ($r_s = 0.174, p = 0.011$) scores. Thus, as the number of interventions to which the child with ASD has experienced increases, so too do parent-rated ASD symptoms and self-rated stress increase. Scrutiny of the caregiver task stress and the Aim Social-Emotional Reciprocity subscale functions motivated the use of quadratic models, but these did not significantly improve the fit. Additionally, no evidence of an association between child age and number of interventions was noted ($r_s = 0.002, p = 0.458$).

The moderating effect of interventions on self-rated parent stress. The study's third hypothesis was addressed using

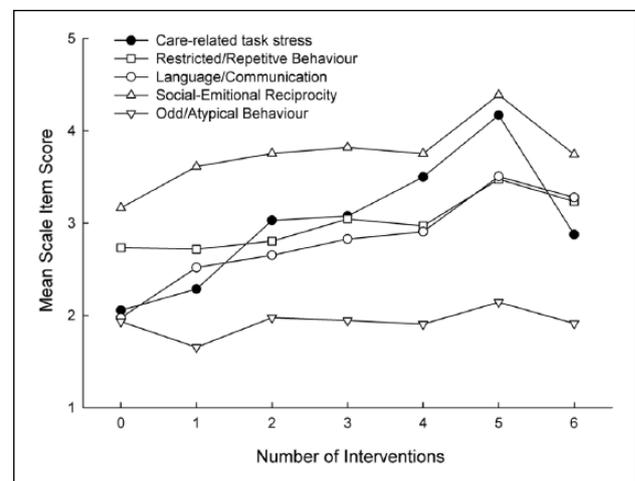


Figure 3. Mean scale item score for the four AIM subscales (open symbols) and the care-related task stress scale (closed circles) as a function of number of interventions.

hierarchical regression procedures to test for a moderating effect of intervention helpfulness (ABA, BT, Dietary, MoE, OT and SLT) on the relationship between parent-rated ASD symptoms (the predictor variable) and care-related task stress (the outcome variable). This involved 24 (6 interventions \times 4 AIM subscales) individual analyses, with the predictor variable scores centred prior to analysis. For all 24 analyses, the predictor variable was entered into Step 1, followed by the moderator variable in Step 2. In Step 3, the predictor \times moderator interaction term was entered. Table 6 presents the five analyses that provided evidence of a moderating effect, that is, a significant interaction term that in turn explained a significant proportion of the model's variance above-and-beyond that accounted for by the predictor and moderating variables (Baron and Kenny, 1986). Here, three interventions (Dietary, MoE and SLT) moderated the impact of Restricted/Ritualized

Table 6. Hierarchical linear regression.

Variable	R^2	ΔR^2	F	B	Beta	T
Moderator: SLT	0.300	0.036*	15.678*			
Restricted/Ritualized Behaviour				1.45	0.521	6.546**
SLT				-0.359	-0.038	0.466
Restricted/Ritualized Behaviour \times SLT				-0.266	-0.192	-2.387*
Moderator: SLT	0.302	0.055*	16.464**			
Social-Emotional Reciprocity				1.589	.496	6.331**
SLT				-1.22	-0.131	1.659
Social-Emotional Reciprocity \times SLT				-0.366	-0.236	-2.986**
Moderator: MoE	0.336	0.065**	17.003**			
Restricted/Ritualized Behaviour				1.239	0.46	5.454**
MoE				-0.041	-0.004	-0.053
Restricted/Ritualized Behaviour \times MoE				-0.343	-0.268	-3.138**
Moderator: MoE	0.282	0.044*	13.461**			
Social-Emotional Reciprocity				1.557	0.510	6.011**
MoE				-0.638	-0.070	-0.819
Social-Emotional Reciprocity \times MoE				-0.304	-0.212	-2.509*
Moderator: Dietary	0.342	0.077*	10.738**			
Restricted/Ritualized Behaviour				1.349	0.495	4.766**
Dietary				-0.183	-0.021	-0.199
Restricted/Ritualized Behaviour \times Dietary				-0.342	-0.288	-2.691**

SLT: speech language therapy; MoE: Ministry of Education.

Summary of moderator effects on caregiver stress.

** $p < 0.001$, * $p < 0.05$.

Behaviours on caregiver task stress, and two interventions (MoE and SLT) moderated the effects of Social-Emotional Reciprocity deficits on caregiver task stress. Here, the direction of the coefficients indicates that these interventions may be buffering the impact of selected ASD symptoms upon parental well-being, with greater helpfulness ratings associated with decreased self-reported parental stress. However, the change in R^2 statistics (ΔR^2) though significant is relatively low, with the addition of the interaction terms explaining an additional 3.5%–7.7% of the variability in caregiver task stress. Thus, our evidence can be taken to partially support the third hypothesis outlined in the introduction.

Discussion

The purpose of this study was to estimate the relationships between caregiver task stress, intervention helpfulness and symptom severity assessed using ratings from parents caring for an ASD child. Sample characteristics were largely consistent with those reported in the literature, including the 4/1 proportion of males-to-females (here 5.8/1). The bias (88%) in female respondents is typical of parental research in the ASD area, and indeed, studies are increasingly trying and failing to recruit greater numbers of fathers (e.g. Mulligan et al., 2012). The average age of symptom emergence, at 23.37 months, is congruent with other reports (Bolton et al., 2012). The percentage of interventions accessed by this New Zealand sample suggests

that intervention cost is a major factor, given that the three most popular interventions are provided free-of-charge either by the Ministry of Education (MoE early intervention) or indirectly by the Ministry of Health (OT/SLT). Unlike other parts of the world (most notably North America), early and intensive behavioural therapies are not provided without cost in New Zealand, and thus this finding serves to highlight the cross-cultural variability in ASD research. A review undertaken by Karst and Van Hecke (2012) concluded ‘behavioural interventions are the most widely available, funded, and utilized form of therapy for children with ASD’ (p. 260), though evidently this does not hold for all countries.

In relation to parental ratings of intervention helpfulness, the midscale (i.e. ≈ 4) ratings for the six interventions mirrors other New Zealand research (Searing et al., 2015) which, using a five-point scale, reported a mean helpfulness rating of 3.02 for ‘professional agencies’. But, while they describe such midscale ratings as ‘mediocre’, we are not so negative. Given the realities of ASD as an incurable and highly challenging disorder, that these midrange data imply that 50% of the sample tended towards the ‘extremely’ or ‘very’ helpful end of the scale might be interpreted as somewhat of an achievement. The lack of significance across the six interventions in terms of helpfulness immediately draws forth comparisons to the well-known ‘dodo bird verdict’ effect in psychotherapy (e.g. Wampold, 2007), in which the overlap of core techniques in the various approaches renders them equally efficacious. Certainly, in

regards to the six interventions evaluated in this study, the degree of shared features would not be insignificant.

While the ABA modality had, albeit not significantly, the highest mean helpfulness rating, this may be due to either parental biases emerging from the high cost of these interventions (Karst and Van Hecke, 2012) or from feeling more engaged and satisfied than with other types of interventions (Regehr and Feldman, 2009). Further analyses indicated that the perceived helpfulness of SLT, MoE and dietary interventions tended to moderate the influence of Restricted/Ritualized Behaviours on caregiver task stress, and higher helpfulness ratings for SLT or MoE interventions influence task stress associated with Social-Emotional Reciprocity dysfunction. In all instances, the intervention buffered the effects of symptom severity on caregiver task stress. Future research examining whether it is specific facets of these interventions that has greater impact on reducing parenting stress is warranted.

An interesting finding from the caregiver task stress scale is the apparent strain involved with advocating for a child with ASD, and also around intervention-related activities. While Plant and Sanders (2007) ranked these activities in the Top 10 list of stressful caregiving tasks, they did not make their Top 4 – which were tasks involving toileting, eating and sleeping. This difference in findings may be explained by the fact that Plant and Sander's sample consisted of children with developmental disorders in general, and did not focus specifically on ASD. Irrespective, advocacy is emerging as a parental task that has received little attention in the literature, even though it may be a major source of pressure. The finding that engagement with interventions is also ranked as one of the highest stress-induced tasks reinforces calls to document how intervention processes impact parents (Karst and Van Hecke, 2012). This finding is important given that approximately 60% of parents participate in the intervention process as 'parent-therapists' (Schertz et al., 2011) and also report greater levels of fatigue (Smith et al., 2010).

To our knowledge, we are the first to report on the use of the AIM scale outside of its creators, and our Cronbach's alphas for the four subscales indicated acceptable internal consistency. While our AIM means were higher than those presented by Kanne et al. (2014), they were also ranked differently. Whereas we found the social-emotional reciprocity subscale to have the greatest impact on function, consistent with other research (Huang et al., 2014), they reported this subscale to have the least influence. Additionally, irrespective of whether parent and child age were controlled for, strong positive relationships were found between the four AIM subscales and the caregiver task stress scale. This finding replicates that of Tobing and Glenwick (2002), who reported that severity of impairment was a predictor of child-related parenting stress. However, the results do not concur with the findings of Davis and Carter (2008), who reported that neither language or

communication deficits nor stereotypical behaviours contributed significantly to parental stress.

For three of the six interventions (MoE, OT, SLT), a relationship between intervention choice (i.e. accessed or not) and caregiver task stress was noted. Interestingly, stress was higher in those whose children were accessing the intervention. However, the fact that the introduction of the AIM total score eliminated these relationships indicates that parent-rated symptom severity may be a better predictor of intervention choice. This is consistent with Shyu et al. (2010), though should not be taken to mean that caregiver stress does not contribute to intervention choice. Given the time and energy demands of parenting a child with ASD, levels of stress may be the factor which ultimately drives a parent to seek help. If so, reducing caregiver task stress through, for example, the adoption of adaptive coping strategies, is still a worthwhile pursuit and may serve to reduce demand on otherwise strained therapeutic services.

Allied to this, the consideration of cognitive factors becomes important given the current study's use of parental ratings of intervention outcomes and caregiving task stress. Falk et al. (2014) reported that social/economic support and parent cognitions (e.g. parental locus of control) mediated the relationship between child-centric factors (e.g. ASD severity) and parental stress. In the current study, it is feasible that positive experiences of home-based interventions might increase perceptions of loci of control, and thus reduce perceived stress and increase helpfulness ratings. Alternatively, if a home-based intervention begins to stretch the resources of parents, or the parents are forced to rely on external agencies to assist with the demands of the intervention, then their locus of control may reduce, with a corresponding decrease in their psychological well-being. Compounding, unrealised developmental expectations may reduce perceived intervention helpfulness, which have been suggested to impact stress (García-López et al., 2016). The future studies should account for such factors when considering the relationship between perceived intervention effectiveness and parenting stress.

In relation to symptom severity and intervention choice, there was no link between the Odd/Atypical Behaviour subscale and the six interventions. The remaining three subscales were linked with intervention choice (see Table 4), with higher mean symptom severity scores noted for those who had engaged MoE, OT and SLT interventions compared to those who had not. However, interpreting these significant relationships is problematic, as our data do not allow scrutiny of whether the interventions are impacting the ASD symptoms, or that symptomology and severity thereof is driving intervention choice. There were no significant differences in AIM subscale scores between those who engaged ABA, BT and dietary interventions and those who had not. The reason for this may be that, unlike the

MoE, OT and SLT interventions, there are no public funds dedicated to these types of interventions, and so there is a natural drift to the government-funded options. Additionally, if parent's perceptions of symptom severity are driving intervention uptake, then reports that parents underestimate severity relative to professionals may be a concern (Bebko et al., 1987).

There was no significant link between child age and the number of interventions accessed, indicating that a multitude of different intervention trajectories exist rather than a stereotypical path. The relationship between the number of interventions accessed and mean caregiver task stress indicated a monotonic positively accelerating function from zero to five interventions utilised, but an unexpected drop for those utilising all six. This may be because those individuals accessing all six interventions have the financial ability to do so, and can draw upon a greater range of support and tolerate the added financial burden of raising a child with ASD (Minnes et al., 2015). Subsequently, they may not be exposed to the same level of stressors. Nock and Kazdin's (2001) finding that socioeconomic disadvantage predicted lack of intervention engagement supports this proposition. The same patterns are noted for AIM subscales with the exclusion of the Oddness/Atypical Behaviour subscale. The implication here is that as symptom severity increases, so too does the number of interventions that are attempted. This again concurs with Shyu et al. (2010), that the chief driver of intervention choice is parent perceptions of their child's symptoms.

When interpreting the findings of this study, a number of methodological limitations must be considered. First, while parent-rated symptom severity scales have existed for some time (e.g. the Childhood-Rating Scale-Parent version: Bebko et al., 1987), there has been some doubt expressed by professionals as to their usefulness (Karst and Van Hecke, 2012). However, it can be argued that the so-called 'objective' clinical methods are equally as vulnerable to biases and contextual effects, as evidenced by the growing concern around ASD and rates of misdiagnosis (Zuckerman et al., 2015). Second, the inclusion of data from fathers may have served to dilute relationships that are moderated by gender, and indeed, in some instances data gathered from fathers and considered insufficient in quantity results in them being excluded from the analysis (e.g. Plant and Sanders, 2007). We justify including fathers on the basis of preliminary analyses indicating a lack of gender effects on relationships of interest. Third, in the moderator analysis only 5/24 interactions reached significance, and the change in variance accounted for was only between 4% and 8% – consistent with ranges reported in other studies (e.g. Plant and Sanders, 2007), but small nonetheless. Fourth, our measure of treatment selection refers to both the past and the present treatments, and so child age and symptom severity may be potential confounding factors. Finally, in considering the impact of

multiple interventions, data did not indicate whether these interventions were engaged serially or simultaneously. Thus, it is not possible to say with confidence if caregiver task stress is related to the number of interventions being used at one time, or if more severe ASD symptoms elicit greater stress and subsequently greater effort to engage interventions.

To summarise, the data from this exploratory study presented evidence that all four core symptoms of ASD, as defined by the Autism Impact Measurement scale, were related to caregiver task stress, with greater parent-rated impairment predicting higher self-reported caregiving stress. Parent ratings of intervention helpfulness did not differ significantly, and the greatest caregiver task stress scores were associated with advocacy and intervention-related activities rather than support tasks. The fact that advocacy was a major source of caregiving stress for parents is an interesting finding and one that has not been adequately examined in the literature. For some core domains of ASD, there was evidence indicating that greater symptom severity was related to the uptake of a greater variety of intervention approaches and, what is more, drove intervention choices. As data are descriptive and causality cannot be inferred, further research is needed to determine the type and quantity of ASD-related interventions involving parents (Zaidman-Zait et al., 2014), parental perceptions of their effectiveness, and their impact upon parental stress. Given the parental investment commonly demanded by ASD interventions, and their impact on intervention effectiveness, further consideration of how the interventions impact the parent and how to buffer this impact will likely lead to greater treatment compliance and benefits for the child for whom they are caring.

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