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Challenging child behaviours positively predict symptoms of posttraumatic stress disorder in parents of children with Autism Spectrum Disorder and Rare Diseases

Michelle Stewart[a], Alexandra Schnabel[a,*], David J. Hallford[a], Jane A. McGillivray[a], David Forbes[b], Madeline Foster[a], Kerrie Shandley[a], Madeleine Gardam[a], David W. Austin[a]

[a] School of Psychology, Deakin University, Geelong, VIC, Australia
[b] Phoenix Australia–Centre for Posttraumatic Mental Health, Department of Psychiatry, The University of Melbourne, Australia

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ABSTRACT

Background: This study investigated the validity of conceptualising elevated stress in parents of children who exhibit challenging behaviour within the framework of posttraumatic stress disorder (PTSD). It was hypothesised that parents of children with autism spectrum disorder (ASD), and parents of children with a rare disease would endorse greater PTSD symptomatology than parents of typically developing (TD) children, and that challenging child behaviours would positively predict PTSD symptomatology.

Method: The Life Events Checklist for DSM-5, Developmental Behaviour Checklist (Parent) and PTSD Checklist for DSM-5 were administered to 395 parents.

Results: Significantly more PTSD symptomatology was reported by parents of children with ASD and parents of children with a rare disease than parents of TD children, and challenging child behaviours positively predicted PTSD symptomatology in both groups.

Conclusion: A PTSD framework may validly explain elevated stress among some parents of children with ASD and parents of children with a rare disease, and has important implications for support delivered to parents by healthcare providers.

1. Introduction

Challenging behaviours exhibited by children with an Autism Spectrum Disorder (ASD) or a rare disease have been shown to be associated with elevated parenting stress (Bitsika & Sharpley, 2004; Hayes & Watson, 2013; Nereo, Fee, & Hinton, 2003). Challenging behaviours are defined as behaviours that are not socially acceptable and can be physically dangerous to the child and family (Emerson, 2001; Holden & Gitlesen, 2006; Matson, Mahan, Hess, Fodstad, & Neal, 2010). Challenging behaviours may lead to exposure to a threatened or actual serious injury or death, which forms part of the definition of a 'traumatic event' identified in the Diagnostic and Statistical Manual of Mental Health Disorders (fifth edition; DSM-5) as a precipitant to the development of posttraumatic stress disorder (PTSD; American Psychiatric Association, 2013).

ASD affects approximately 1.47% of the world's population (Centers for Disease Control & Prevention, 2014), and is a neurodevelopmental disorder defined by deficits in socio-communicative behaviours, the presence of stereotypical behaviours and a

* Corresponding author at: School of Psychology, Deakin University, 221 Burwood Highway, Burwood, Melbourne, VIC, 3125, Australia.
E-mail address: ali.schnabel@deakin.edu.au (A. Schnabel).

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restricted range of interests (American Psychiatric Association, 2013). Although not all children with ASD exhibit challenging behaviours, when present, these behaviours have a greater physical and emotional impact on parents than core ASD psychopathology (Bitsika & Sharpley, 2004; Myers, Mackintosh, & Goin-Kochel, 2009). Prevalence rates of challenging behaviours among children with ASD vary from 63.4% to 94% (Jang, Dixon, Tarbox, & Granpeesheh, 2011; Matson, Wilkins, & Macken, 2009; McTiernan, Leader, Healy, & Mannion, 2011; Murphy, Healy, & Leader, 2009). Challenging behaviours that place the child and/or parent at risk of harm include physical aggression and self-injurious behaviours (McClintock, Hall, & Oliver, 2003), suicidal behaviours (Mayes, Gorman, Hillwig-Garcia, & Syed, 2013), elopement (Lang et al., 2010) and pica (Mayes & Zickgraf, 2019).

Aggressive behaviours include pushing, hitting, kicking, and biting self or others (Farmer & Aman, 2011). These behaviours have been associated with hospitalisation and/or police involvement (Myers et al., 2009). In a sample of 1380 parents of children with ASD, 56% reported their child currently engaged in some degree of physical aggression towards caregivers, while 68% reported a history of this (Kanne & Mazurek, 2011).

Self-injurious behaviours, including repeated head-banging with fists or against walls, hand-biting and excessive self-scratching (McClintock et al., 2003), constitute one of the main causes of hospitalisation in children with ASD (Mandell, 2008). A meta-analysis of studies conducted over the past 30 years identified that individuals with ASD were six times more likely to engage in self-injurious behaviours than those without ASD (McClintock et al., 2003).

Suicidal ideation or attempts have been identified in a minority of children with ASD. For example, in a sample of 791 children with ASD, 10.9% exhibited suicidal ideation and 7.2% had made an attempt on their life (Mayes et al., 2013). These findings represent a 28-fold elevation in suicidal behaviour in children with ASD compared to typically developing (TD) peers.

Elopement occurs when a child wanders or runs from a specified area without parent permission (Lang et al., 2010). In a sample of 1200 children with ASD, 49% had eloped and 26% had been missing long enough to cause concern for the child's safety (Anderson et al., 2012). Elopement is associated with the highest standardised mortality rate in children with ASD between the ages of five and ten (Shavelle, Strauss, & Pickett, 2001).

Pica is the repetitive consumption of non-food substances with no nutritional value, such as paper, hair, soap, paint, pebbles and soil (American Psychiatric Association, 2013). In a sample of 1462 children with ASD, 12% had pica; in this sample, the most common substances consumed were crayons, followed equally by soap, paper, faeces, dirt, and Play-Doh (Mayes & Zickgraf, 2019). Pica can result in serious health complications, including poisoning, severe gastrointestinal impacts, and repeated surgeries to remove objects (Bell & Stein, 1992; Matson, Belva, Hattier, & Matson, 2011). There are reported instances of long-term pica causing death in individuals with developmental disabilities (Byard, 2014; Williams & McAdam, 2012).

There is emerging evidence to suggest that some children with a rare disease also exhibit challenging behaviours. A rare disease is defined as a life threatening or chronically debilitating condition, generally affecting less than 0.05% of the population (Anderson, Elliott, & Zurynski, 2013). Although statistically uncommon, there are over 8000 rare diseases identified worldwide, collectively affecting 6–10% of Australians (Knight & Senior, 2006; Zurynski, Frith, Leonard, & Elliott, 2008).

Rare diseases are commonly further defined as "behaviour-related" or "non-behaviour related". As the nomenclature suggests, behaviour-related rare diseases are characterised by challenging behaviours. A study comparing parenting stress in 244 parents of children with non-behaviour related rare diseases and behaviour-related rare disease found that parents of children with behaviour-related rare diseases such as Fragile x syndrome, Kabuki syndrome, and Prader-Willi syndrome reported higher levels of stress (Dellve, Samuelsson, Tallborn, Fasth, & Hallberg, 2006).

Duchenne Muscular Dystrophy (DMD) is an example of a rare disease associated with challenging behaviours. Mothers of children with DMD have reported higher levels of stress in the presence of significantly challenging behaviours (Nereo et al., 2003). Reports indicated that challenging behaviours were experienced as more stressful for mothers than the physical demands of the disease alone (Nereo et al., 2003). Ricotti et al. (2015) reported emotional and behavioural problems to be highly prevalent in a cohort of 87 children with DMD, with 25% scoring in the clinical range for internalising problems and 16% in the clinical range for externalising problems (e.g., oppositional/aggressive behaviours).

Smith-Magenis Syndrome (SMS) is another rare disease characterised by a neuro-behavioural phenotype that includes impulsivity, aggression and self-injurious behaviours (Dykens & Smith, 1998). These characteristics have been shown to be amongst the strongest predictors of parental problems, including stress among families with a child diagnosed with SMS (Fidler, Hodapp, & Dykens, 2010).

In addition to the shared experience of managing challenging behaviours, parents of children with ASD and rare diseases share common support difficulties, include unmet service needs (Dellve et al., 2006; Taylor & Seltzer, 2010), low levels of perceived family and social support (Bromley, Hare, Davison, & Emerson, 2004; Pelentsov, Laws, & Esterman, 2015), and low self-confidence in their own ability to manage their child's behaviours (Bitsika & Sharpley, 2004; Lauder, Sinclair, & Maguire, 2018).

It appears reasonable to propose that a subpopulation of parents of children with ASD and parents of children with a rare disease who encounter challenging behaviours may be exposed to threatened or actual serious injury and, in more severe cases, threatened or actual death. When considering repeated exposure to these adverse events, elevated stress in parents may be appropriately conceptualised within the framework of posttraumatic stress.

The DSM-5 (American Psychiatric Association, 2013) identifies exposure to pre-defined traumatic events (Criterion A) as an essential feature in the development of PTSD. Traumatic events are defined as events involving exposure to actual or threatened death, serious injury, or sexual assault. It is proposed that traumatic events encountered by these two cohorts of parents may be characterised by a threat to the life of their child (e.g., suicidal behaviours and elopement), an actual or threatened serious injury to their child (e.g., self-injurious behaviours, physical aggression) or the life of a sibling, parent or other person (e.g., physical aggression).

Casey et al. (2012) adopted a posttraumatic stress framework to explore parent responses to the event of receiving their child's ASD diagnosis. The posttraumatic stress symptoms (PTSS) framework can be applied when there is no event that satisfies the Criterion A (traumatic event) for DSM-5 PTSD, but the subject still exhibits PTSD symptomatology. After surveying 265 parents (245 mothers), Casey et al. reported that 20% of parents endorsed moderate-to-high levels of PTSS. Further investigation revealed that 14% and 15% of parents experienced clinically significant intrusive and hyperarousal symptoms, respectively (Casey et al., 2012).

PTSD symptomatology in parents of children with ASD has also been reported in studies utilising physiological measures, including saliva cortisol levels. Seltzer et al. (2010) reported lower levels of cortisol in mothers of adolescents and adults with ASD, and Foody, James, and Leader (2014) found lower cortisol levels in mother-father dyads of younger children with ASD when compared with parents of TD children. Lower levels of cortisol are associated with chronic stress; this suppression of cortisol is conceptualised as a symptom of over-activation of the hypothalamic-pituitary-adrenocortical (HPA) axis responsible for cortisol regulation (Gunnar & Vazquez, 2001). Exposure to acutely traumatic or highly stressful events typically results in an increase in cortisol, yet chronic exposure to such events would demand high levels of cortisol that are not possible to maintain; such exposure leads to hypocortisolism (Gunnar & Vazquez, 2001). Both studies identified the influence of specific challenging child behaviours on cortisol levels, including self-injurious behaviours (Seltzer et al., 2010) and oppositional behaviours (Foody et al., 2014). Seltzer et al. (2010) noted that reduced or blunted cortisol responses have also been documented in samples of combat soldiers, Holocaust survivors, and individuals with diagnosed PTSD (Heim, Ehlert, & Hellhammer, 2000; Miller, Chen, & Zhou, 2007; Yehuda, Boisoneau, Lowy, & Giller, 1995). Thus, it seems reasonable to suggest that there may to be a subpopulation of parents of children with ASD who appear to exhibit cortisol profiles that are indirectly comparable to a clinical population of individuals exposed to traumatic stressors. We are not aware of any research examining posttraumatic stress in cohorts of parents of children with a rare disease.

The purpose of the current study is to investigate if a traumatic stress framework can be utilised to further our understanding of elevated stress in parents of children who exhibit challenging behaviours, specifically, in parents of children with ASD and parents of children with a rare disease. Parents of children with a rare disease were included as a comparative clinical parenting group due to evidence that this group shares many challenges with parents of children with ASD. Shared challenges reported by both groups include uncertainty around cause, cure and prognosis, challenged communication and attachment, unmet service needs, low levels of perceived family and community support and understanding, and low confidence in their ability to manage their child's condition. By including this group, a preliminary investigation of whether elevated traumatic stress in the context of challenging ASD-related behaviours was a phenomenon likely to be somewhat specific to parents of children with ASD or may apply to other parenting populations managing other chronic (but non-ASD) conditions.

The DSM-5 PTSD diagnostic criteria is utilised to explore whether challenging child behaviours could predict traumatic stress in parents, operationalised herein as PTSD symptomatology. It was hypothesised that: (1) parents of children with ASD or a rare disease would endorse higher levels of PTSD symptomatology than the control group of parents of TD children, and (2) challenging behaviours exhibited by children in these clinical groups would positively predict PTSD symptomatology in parents.

2. Method

2.1. Participants and procedure

Participants were recruited throughout Australia using social media, online ASD forums, ASD support groups, ASD-relevant non-government organisations and rare disease specific support groups and organisations. In total, 395 parents (n = 379 mothers) of children aged between 5 and 20 years completed an online questionnaire. There were three groups: parents of children with ASD (n = 226, 96.9% mothers), parents of children with a rare disease (n = 139, 94.2% mothers), and parents of TD children (n = 30, 96.7% mothers). Descriptive statistics for the three groups are presented in Table 1.

It was not feasible to conduct individual assessments to confirm ASD diagnoses of the children. Instead, parents were asked to identify the type of registered health professional who provided the diagnosis and the child's specific ASD diagnosis (see Table 1). Reported diagnoses included autism (39%), Asperger's syndrome (34%), high functioning autism (18%), and PDD-NOS (9%). Common mental and physical health comorbidities for the ASD group included attention deficit hyperactivity disorder (20.4%), anxiety-related disorders (13.7%), learning disorders (5.3%), medical conditions such as epilepsy (5%), and intellectual disability

Table 1
Descriptive Statistics of Sample by Group.

	ASD	RD	TD
Age of parents (*M, SD*)	42.2 (6.3)	42.3 (6.7)	39.9 (5.0)
Age of child (*M, SD*)	13.6 (3.8)	10.7 (5.6)	10.0 (3.7)
Gender of child (% male)	80%	55%	47%
Age at diagnosis (*M, SD*)	5.0 (3.0)	4.9 (5.1)	N/A
Health professional who diagnosed child (%)	Paediatrician (53%) Psychologist (28%) Psychiatrist (10%) GP or other (9%)	Other (19.7%) Paediatrician (14.2%) GP (0.5%) Psychologist (0.3%)	N/A

Note: ASD = Autism Spectrum Disorder, RD = Rare Disease, TD = Typically developing.

(4.9%). Reported rare diseases included Ehlers Danlos Syndrome (n = 7), Duchenne Muscular Dystrophy (n = 5), Eosinophilia Esophagitis (n = 5), Tuberous Sclerosis (n = 5), Fabry Disease (n = 4) and Smith-Magenis Syndrome (n = 4).

Approval to conduct the study was granted by the Deakin University Human Research Ethics Committee. If parents had more than one child with an ASD diagnosis (n = 10) or more than one child with a rare disease (n = 22) they were asked to consider the child who exhibited the most challenging behaviours when completing the questionnaire. Informed consent was implied after the plain language statement was displayed and participants continued onto complete the questionnaire.

2.2. Measures

Sociodemographic information collected included parent age, gender, marital status, location (metropolitan, regional, rural), and number of children. For each child, the parent was asked to provide year of birth, gender, and any psychological, medical, or learning disorder diagnoses.

The Life Events Checklist for the DSM-5 (LEC-5; Weathers, Blake et al., 2013) was used to screen for parent's exposure to traumatic stressors throughout their lifetime. There are sixteen events in total and one additional item assessing for any extraordinarily stressful event. For the purposes of this study, only direct experiences of a LEC-5 event (i.e., 'happened to me') were included. The LEC-5 demonstrates adequate psychometric properties as a stand-alone assessment of traumatic exposure, with good interrater reliability across all items (kappa = .61) and retest reliability (r = .82, p < .001) (Gray, Litz, Hsu, & Lombardo, 2004).

The PTSD Checklist for the DSM-5 (PCL-5) (Weathers, Litz et al., 2013) was used to assess whether parents reported experiencing DSM-5 symptoms of PTSD during the past month. Although the current study retained the instructions provided by this measure, parents were asked to "keep in mind the experience of parenting your child who exhibited the most challenging behaviours" in order to direct their focus to parenting experiences when completing the measure. The PCL-5 provides a total symptom severity score (range 0–80) and symptom clusters which align with DSM-5 PTSD criterions. A provisional diagnosis can be made with a total PCL-5 score of 38 or above, or a more stringent approach can be adopted which requires the endorsement of items as a two on the scale ('2 = *moderately*' or above) to fulfil DSM-5 PTSD diagnostic criteria algorithm in terms of the number of Criterion B, C, D and E symptoms required for diagnosis. The PCL-5 demonstrates good internal consistency (Cronbach's alpha = .95) (Armour et al., 2015).

The Developmental Behaviour Checklist (Parent version; DBC-P) (Einfeld & Tonge, 2002) was used to assess for behavioural and emotional disturbances in children. Parents were asked to consider their child's behaviours over the past six months. A three-point Likert-scale is used to indicate frequency of behaviour (0 = *not true as far as you know*, 1 = *somewhat or sometimes true*, 2 = *very true or often true*) for 96 items. The DBC-P provides a Total Behaviour Problem Score (TBPS), with scores of 46 or greater indicating clinically significant levels of disturbance. Five subscales can also be derived: disruptive/anti-social behaviour ("abusive; irritable; kicks; hits"), self-absorbed ("preoccupied with trivial items; hums; grunts"), communication disturbance ("talks to self; talks in whispers"), anxiety ("separation anxiety; phobias; cries easily"), and social relating ("doesn't show affection; aloof; doesn't respond to other's feelings). The TBPS has been demonstrated to have good reliability (Intrarclass correlation [ICC] = .8, 99% CI [.59, .90]), validity, and internal consistency (Cronbach's alpha range = .71–.91) (Einfeld & Tonge, 1995).

2.3. Data analytic strategy

Data was analysed using IBM SPSS Statistics, Version 25. Pearson correlations were conducted to assess the bivariate associations between the study variables. To address our first hypothesis that parents of children with ASD or a rare disease would endorse higher levels of PTSD symptomatology than the control group of parents of TD children, we conducted an analysis of covariance (ANCOVA) with PCL-5 scores as the dependent variable while controlling for exposure to LEC-5 traumatic stressors. Two separate multivariate analysis of covariance (MANCOVA) were then conducted with each LEC-5 traumatic stressor as covariates, to identify individual differences in distinct experiences of parental lifetime trauma exposure in the two clinical parent groups. Partial eta squared is reported as a measure of effect size which provides an estimate of the proportion of the total variance accounted for by the factor under consideration. Small, medium, and large effects were operationalized as .01, .06, and .14, respectively (Richardson, 2011). A backward variable selection technique was implemented, and LEC-5 event covariates with the highest p-value were removed one at the time until all factors were significant at the p < .05 level.

To address our second hypothesis that challenging behaviours exhibited by children in these clinical groups would positively predict PTSD symptomatology in parents, multiple regression analyses were performed, with PCL-5 scores regressed against the DBC-P behavioural domains for both parent groups. Such analyses identified how much variance in PCL-5 scores was accounted for by DBC-P domains of challenging behaviour, including which behavioural domains predicted unique variance in PCL-5 scores.

3. Results

Correlations between the demographics and other variables of interest are presented in Table 2. Given the small number of fathers in the sample (n = 16), statistical analyses were run twice (with and without fathers) to determine the impact of this. As the results did not differ significantly, the subsequent analyses are for the total sample (both mothers and fathers).

3.1. Posttraumatic stress amongst parents

Initially, parents in each group who met the clinical threshold (> 38) on the PCL-5 were identified. Of the 226 parents of children

Table 2
Inter-correlations of Relevant Demographic, Behavioural and PTSD Variables.

	Child gender	Child age	Age at dx	TBPS	D/A	S-A	CD	Anx	S-R	PCL-5	M	*SD*
Number of children	.05	.17**	.08	.25**	.24**	.21**	.26**	.10*	.14**	.07	1.95	1.01
Child gender		.04	.02	−.17**	−.15**	−.17**	−.17**	−.09	−.16**	−.16**	1.37	.48
Child age			.47**	−.00	−.03	−.04	.01	.03	.12*	.12*	10.92	4.58
Age at dx				−.01	−.02	−.05	−.02	.00	.11*	.06	5.01	3.96
TBPS					.90**	.90**	.89**	.75**	.71**	.57**	56.77	35.65
D/A						.73**	.72**	.63**	.60**	.49**	18.46	12.23
S-A							.83**	.58**	.56**	.51**	14.88	11.63
CD								.63**	.60**	.52**	7.68	5.88
Anx									.56**	.48**	6.58	4.19
S-R										.47**	5.18	3.76
PCL-5											22.61	16.92

Note: dx = diagnosis; TBPS = Total Behaviour Problem Score from Developmental Behaviour Checklist-Parent version (DBC-P); D/A = disruptive/antisocial behavioural domain of DBC-P; S-A = self-absorbed behavioural domain of DBC-P; CD = Communication disturbances behavioural domain of DBC-P; Anx = anxiety behavioural domain of DBC-P; S-R = social relating behavioural domain of DBC-P; PCL-5 = total score on PTSD Checklist for DSM-5.

* $p < 0.05$.

** $p < 0.01$.

with ASD, 53 (23.5%) met or exceeded the threshold and 24 (17.3%) of the parents of children with a rare disease met or exceeded the threshold. None of the parents of TD children met the clinical threshold on the PCL-5. Using a more stringent approach, whereby respondents met the clinical threshold *and* endorsed the required number of DSM-5 PTSD criteria for consideration of a provisional diagnosis, 42 (18.6%) parents of children with ASD and 17 (12.2%) parents of children with a rare disease endorsed the required number of criteria.

The ANCOVA noted significant group differences in PCL-5 scores while controlling for exposure to traumatic events (see Table 3), with parents of children with ASD demonstrating the highest mean PCL-5 scores, followed by parents of children with rare diseases, and parents of typically developing children. The covariate of exposure to traumatic events was also significant.

To assess the significance of specific traumatic events parents were exposed to in their experience of parenting their children, MANCOVAs were conducted with each LEC-5 traumatic stressor as covariates, utilising a backward selection technique until only significant ($p < .05$) events remained. The two clinical groups of parents of children with ASD and parents of children with a rare disease were analysed in separate MANCOVAs.

For parents of children with ASD, five LEC-5 traumatic events remained significant (see Table 4). Group accounted for 30% of the variance in PCL-5 scores for parents of children with ASD. The mean difference for scores on the PCL-5 indicated parents of children with ASD reported a mean score 19.2 points higher than parents of TD children, which represented a large effect size, partial eta squared = .34.

For parents of children with a rare disease, four LEC-5 traumatic events remained significant (see Table 4). Group accounted for 20% of the variance in PCL-5 scores for parents of children with rare diseases. The mean difference for scores on the PCL-5 indicated parents of children with rare diseases reported an estimated a mean score 10.6 points higher than parents of TD children, which represented a large effect size, partial eta squared = .14.

3.2. Challenging behaviours as predictors of trauma symptomatology

The mean TBPS on the DBC-P for parents of children with ASD was 74.96 (*SD* = 29.8). The percentage of parents of children with ASD who had a TBPS in excess of 46, indicative of clinical levels of emotional and behavioural disturbances, was 83.1%. The mean TBPS on the DBC-P for parents of children with a rare disease was 33.98 (*SD* = 27.82), and 29.5% of parents scored in excess of 46. The mean TBPS on the DBC-P for parents of TD children was 25.3 (*SD* = 24.77), and 16.5% of parents scored in excess of 46.

There was a significant difference in levels of challenging child behaviours between the groups, with parents of children with ASD experiencing significantly greater challenging behaviour compared to parents of typically developing children, $t(40.99) = 10.05$, $p < 0.001$. Parents of children with a rare disease did not experience significantly greater challenging child behaviour compared to parents of typically developing children, $t(167) = 1.57$, $p = .116$.

Table 3
ANCOVA of PTSD Checklist for DSM-5 Scores when Controlling for Life Events Checklist for DSM-5 Items (N = 395).

Variable	$M_{group\ 1}$	$M_{group\ 2}$	$M_{group\ 3}$	F	Sig
Group Direct experience of traumatic event	10.88	26.38	19.01	19.93 56.37	< .00 < .00

Note: Group 1 = parents of typically developing children (control), Group 2 = parents of children with ASD, Group 3 = parents of children with a rare disease.

Table 4
MANCOVA of PTSD Checklist for DSM-5 Scores for Parents when Controlling for Life Events Checklist for DSM-5 Items.

LEC-5 Traumatic Events	*M (SD)*[a]	*F*	*p*	η_p^2
Parents of Children with ASD	27.07 (16.48)			
Natural disaster		5.33	< .05	0.02
Physical assault		5.17	< .05	0.02
Assault with a weapon		9.82	< .00	0.04
Life threatening illness or injury		11.44	< .00	0.04
Serious injury, harm, death you caused someone		5.73	< .05	0.02
Parents of Children with a Rare Disease	18.55 (16.18)			
Natural disaster		4.21	< .05	0.03
Exposure to toxic substance		8.76	< .00	0.06
Sudden accidental death		9.06	< .00	0.06
Group		10.34	< .00	0.06

[a] Mean and standard deviation of group scores on the PCL-5.

To explore the association between the frequencies of a child's challenging behaviours and PTSD symptomatology of parents in both ASD and rare disease groups, multivariate regression analyses were performed. The dependent variable (PCL-5) was individually regressed against the DBC-P behavioural domains for both parent groups (see Table 5).

For parents of children with ASD, two DBC-P domains, *disruptive-antisocial* and *anxiety,* were significant predictors, and accounted for 30.4% (95% CI .22–.41; $R^2 = .32$) of the variance in PCL-5 scores ($F = 32.4$, $p < .001$). Of note, 29 of the 42 parents of a child with ASD who exceeded the clinical cut-off score on the PCL-5 and DSM-5 PTSD criteria reported TBPS scores above the clinical threshold (> 46). The remaining 13 parents reported TBPS scores of 40 or greater.

For parents of children with rare diseases, one DBC-P domain, *anxiety,* was a significant predictor, with *social relating* approaching significance ($p = .056$). These domains accounted for 19% (95% CI .09–.32; $R^2 = .21$) of the variance in parent's PCL-5 scores ($F = 17.19$, $p < .001$). Of note, 8 of the 17 parents of a child with a rare disease who exceeded the clinical cut-off score on the PCL-5 and DSM-5 PTSD criteria reported TBPS scores above the clinical threshold (> 46).

4. Discussion

The aim of the current study was to investigate if a traumatic stress framework can be applied to further our understanding of elevated stress in parents of children who exhibit challenging behaviours. It was hypothesised that: (1) parents of children with ASD or a rare disease would endorse higher levels of PTSD symptomatology than the control group of parents of TD children, and (2) challenging child behaviours exhibited by children with ASD or a rare disease would positively predict PTSD symptomatology in their parents.

After controlling for exposure to DSM-5 PTSD traumatic stressors required for the recognised development of PTSD, parents of children with ASD and parents of children with a rare disease both reported significantly higher levels of PTSD symptomatology relative to the TD parent group. Furthermore, when adopting more stringent criteria when interpreting self-reported PTSD symptomatology, a substantial minority of parents of children with ASD (18.6%) and parents of children with a rare disease (12.2%) reported trauma symptomatology consistent with a provisional PTSD diagnosis. No parents of typically developing children met the clinical cut-off on the PCL-5 or the DSM-5 PTSD stringent diagnostic criteria for consideration of a provisional PTSD diagnosis. These findings support the first hypothesis. The finding that 18.6% of parents of children with ASD reported PTSD symptomatology (criteria B–F) consistent with consideration for a provisional diagnosis of PTSD builds upon the sole prior study to date by Casey et al. (2012), who reported 20% of their parent sample experienced moderate-to-high levels of trauma symptomatology. While the events differ

Table 5
Multivariate Regression Analysis of Post-Traumatic Stress Symptoms of Parents of a Child with Autism Spectrum Disorder (N = 226) and Parents of a Child with a Rare Disease (N = 139) with Developmental Behaviour Checklist (Parent Version) Domains.

Behavioural Domain	*B* [95% CI]	*SE B*	β	*p*
Parents of a Child with ASD				
Disruptive-antisocial	0.26 [.03, .49]	0.11	.17	.023
Self-absorbed	0.25 [-.03, .54]	0.14	.16	.089
Communication disturbances	0.38 [-.20, .97]	0.29	.12	.199
Anxiety	0.67 [.12, 1.22]	0.28	.16	.017
Social relating	0.53 [-.11, 1.17]	0.33	.11	.108
Parents of a Child with a Rare Disease				
Disruptive-antisocial	−0.23 [-.68, .21]	0.23	−.14	.304
Self-absorbed	0.14 [-.27, .55]	0.21	.08	.501
Communication disturbances	0.49 [-.46, 1.44]	0.48	.14	.310
Anxiety	1.04 [.48, 2.04]	0.50	.24	.040
Social relating	0.85 [-.23, 1.72]	0.44	.19	.056

between studies (ASD diagnosis versus challenging behaviours), the self-reported prevalence rates are comparable, and highlight the importance of continuing to exploring the relevance of a post-traumatic stress framework for understanding some parent's mental health.

Challenging child behaviours exhibited by children with ASD and rare diseases were identified as positive predictors of PTSD symptomatology in their parents, providing support for hypothesis two. Disruptive-antisocial behaviours (e.g., kicks, hits, abusive) and anxiety-related behaviours (e.g., phobias, cries easily) accounted for 30.4% of variance in PTSD symptomatology of parents of children with ASD. Further, 69% of parents of children with ASD who reported challenging child behaviours within the clinical threshold range also exceeded the clinical cut-off score for consideration of a PTSD provisional diagnosis. In particular, the antisocial behaviours endorsed by these parents are considered to place the child and others at increased risk of threatened or actual serious injury or death. This increases potential for exposure to a Criterion A stressor required for a PTSD diagnosis. Importantly, exposure to these challenging behaviours remained significant predictors of PTSD symptomatology when controlling for significant traumatic life events that participants had experienced outside of their parenting context.

For parents of children with a rare disease, anxiety-related behaviours were the only positive predictor of PTSD symptomatology, accounting for 19% of variance in parents' PTSD symptomatology. Further, 47% of parents of children with a rare disease who reported child behaviours within the clinical threshold range also exceeded the clinical cut-off score for consideration of a provisional PTSD diagnosis. Interestingly, while parents of children with ASD endorsed significantly greater challenging child behaviours than parents of TD children, parents of children with a rare disease did not. This may be due to heterogeneity within the rare disease sample with regards to a lower frequency of behaviour-related rare diseases within the sample. As a result, challenging child behaviours may have been less likely to result in events that may lead to threatened or actual injury or death to the child and/or others, and thus not best be encapsulated by a traumatic stress framework. Despite the sample composition, a predictive relationship was seen between challenging child behaviours and PTSD symptomatology in this group of parents.

The findings presented in the current study are consistent with previous studies that have demonstrated challenging child behaviours contribute to increased parental stress (e.g., Brei, Schwarz, & Klein-Taman, 2015; Lecavalier, Leone, & Wiltz, 2006). The current study did not directly identify a DSM-5 PTSD traumatic stressor. Instead parents were asked to reflect on their child's most challenging behaviours over the past month when completing the PCL-5. Despite this limitation, 18.6% of parents of children with ASD and 12.2% of parents of children with rare diseases self-reported a psychological profile consistent with someone experiencing PTSD. This is substantially higher than the general Australian population PTSD prevalence rate of 6.4% (Australian Bureau of Statistics, 2007).

The MANCOVA also demonstrated that exposure to five of the 16 LEC-5 traumatic stressors (*natural disaster*, *physical assault*, *assault with a weapon*, *life threatening illness or injury*, and *serious injury, harm of death you caused someone)* were also significant contributors to the variance in PCL-5 scores for parents of children with ASD. Apart from *natural disaster*, a parent of a child with ASD could potentially encounter these traumatic stressors as part of their parenting experience, given the challenging behaviours endorsed.

The significance of *natural disaster* in this model is of interest, given that other non-child related events such as *combat or exposure to war zone* or *serious work accident* were not significantly related to parental PTSD symptomatology in this sample. Examples in the LEC-5 for *natural disaster* include flood, hurricane, tornado, and earthquake. Despite the provision of these examples, it is hypothesised that some parents may have responded to this item with a different interpretation of 'natural disaster', which drawing upon Casey et al.' (2012) research, may be the event of receiving their child's ASD diagnosis. Qualitative research also illustrates the psychological impact of diagnosis for some parents, who express that the event of their child's diagnosis was experienced as a form of death for the child they had expected to parent (Fernańdez-Alcántara et al., 2016).

A further limitation of this study is the under-representation of fathers within the sample; 96% of the present sample was comprised of mothers. Therefore, the results may not be generalisable to fathers. The inclusion of a more representative sample of fathers in future research is important as males and females can exhibit different traumatic stress profiles. Women tend to have a higher risk of PTSD than men (Olff, 2017), therefore a gender-balanced sample may yield a different picture to the current results.

There were also cases where parents identified having more than one child with a diagnosis of ASD (n = 10; 4.24%) or a rare disease (n = 22; 15.83%). Although these parents were asked to consider the child who engaged in the most challenging behaviours when completing the questionnaire, it cannot be assumed that they were able to fully separate their children's behaviours. As such, this is recognised as a potentially confounding variable for this subset of parents within the sample.

Lastly, the current study identified that challenging behaviours accounted for 29.5% of the variance in trauma scores on the PCL-5 for parents of children with ASD. While this is a substantial amount of variance, there remains another 70.5% that is unexplained. Additional research is warranted to investigate the other factors that contribute to an increased risk of self-reported trauma symptomatology, as well as protective factors that may moderate the relationship between challenging child behaviours and the development of PTSD symptoms in parents, for example, parent resilience, access to appropriate services and social support.

4.1. Implications

Health professionals need to be aware that some parents of children with ASD and parents of children with a rare disease may be exposed to events related to their child's behaviours that lead to the experience of traumatic stress. The presence of even a few typical traumatic stress symptoms in parents has been proposed to compromise their efficacy as caregivers (Cabizuca et al). For example, avoidance of re-experiencing certain behaviours may act as a barrier to accessing clinically indicated levels of support for their child (Stuber, Christakis, Houskamp, & Kazak, 1996). Barriers to treatment are considered to place the family at risk of encountering

ongoing challenging behaviours, which is likely to further exacerbate the presence of traumatic stress (Stewart et al., 2017). The implications here are two-fold; child intervention aimed at reducing behaviours is important to improve safety and quality for parent and child (Seltzer et al., 2010) and the importance of evidence-based support for parent mental health.

The Australian Guidelines for the Treatment of Adults with Acute Stress Disorder and PTSD (Phoenix Australia – Centre for Posttraumatic Mental Health, 2013) indicate trauma-focussed cognitive behaviour therapy as best practice intervention. Research investigating traumatic stress in parents of children with ASD is still in its infancy and, as such, ongoing research is required to explore how best practice intervention could be applied. It is recommended that future research investigating best practice consider the implications of parents potentially experiencing chronic and ongoing traumatic stressors.

Although further research is required, the introduction of brief trauma screening measures like the PCL-5 would assist health professionals in determining whether parents require further assessment to determine whether they have experienced a traumatic stressor and are subsequently exhibiting trauma psychopathology.

Results from the current study provide evidence of PTSD symptomatology in parents of children with ASD, and that greater levels of such symptomatology are predicted by the presence of challenging child behaviours that involve an actual or threatened serious injury, or threat to life. These findings highlight the importance of health professionals being cognisant of the notion that parents of children with ASD may be exposed to traumatic stressors resulting from challenging child behaviours, and in response, exhibit symptomatology that could be conceptualised within a traumatic stress framework.

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