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PTSD IN PARENTS OF CHILDREN WITH ASD

An initial examination of post-traumatic stress disorder in mothers of children with autism spectrum disorder: challenging child behaviours as Criterion A traumatic stressors

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Abstract

Parenting a child with autism spectrum disorder (ASD) is associated with high levels of stress. Several studies have conceptualised this as a traumatic stress response to challenging child behaviours such as self-harm, suicidal ideation and physical aggression towards caregivers. In the present study we explored the relevance of a trauma-based diagnostic framework to a sample of 30 mothers (M age = 42.97, SD = 5.82) of children with ASD (M age = 12.43, SD = 3.15). Participants were interviewed using the Clinician-Administered PTSD Scale for DSM-5 (CAPS-5) for post-traumatic stress disorder (PTSD) and an abbreviated Mini International Neuropsychiatric Interview to assess for comorbidity. Three participants were excluded as they met criteria for PTSD from a traumatic event unrelated to their parenting experience. Of the remaining 27 participants, six (22.2%) met criteria for PTSD in the context of traumatic parenting experiences. Descriptions of traumatic events experienced are summarised. Results suggest that, for some parents, challenging child behaviours such as physical violence toward the caregiver from the child, self-injurious behaviours and suicidal behaviours function as traumatic stressors as per Criterion A of PTSD (American Psychiatric Association, 2013). This has implications for health professionals engaged with parents of children with ASD, who should consider the possibility of PTSD when challenging behaviours of a potentially traumatic nature are present.

Lay Summary

This study found that some challenging behaviours exhibited by children with autism spectrum disorder (ASD) can be traumatic for parents, and lead to the development of post-traumatic stress disorder (PTSD). Some of these behaviours included self-harming behaviours like head banging, expressing suicidal urges, and becoming physically aggressive towards parents during meltdowns.

Keywords: diagnosis, post-traumatic stress disorder, parents, autism spectrum disorder, traumatic stress

Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterised by deficits in socio-communicative behaviours, and repetitive patterns of behaviour that may be restrictive in nature (American Psychiatric Association, 2013). ASD is estimated to affect 2-4% of the population (May, Scibberas, Brignell, & Williams, 2017). Some individuals with ASD may display symptoms of a disruptive and/or challenging nature, which can include behaviours such as meltdowns, physical aggression and violence toward others, non-suicidal self-injurious behaviours such as head-banging (McClintock, Hall, & Oliver, 2003) and suicidal behaviours at greater rates than neurotypical individuals (Segers & Rawana, 2014).

It has been demonstrated that higher frequency and diversity of challenging behaviours are predictive of greater parental depression and stress (Ekas & Whitman, 2010). Challenging behaviours have been identified as a better predictor of maternal social-emotional functioning than core DSM-5 symptoms of ASD in their children regarding

interpersonal relating and communication impairments (Ekas & Whitman, 2010). Machado Junior et al. (2016) reported that severe symptoms of depression and anxiety were significantly more common in parents of children with severe behavioural problems (43%), while only 16% of parents of children with mild behavioural issues noted similar symptoms of depression and anxiety. In a longitudinal study assessing child behavioural problems and maternal depression in mothers of children with autism, the positive correlation between behavioural problems and maternal depression was stable over a three-year measurement period (Baker et al., 2011).

Some parents of children with ASD identify that challenging and unpredictable behaviours constitute the most difficult aspect of their parenting experience, which they rate as more distressing than cognitive or communicative difficulties and the high need of practical support required by their child (Bitsika & Sharpley, 2004; Kissel & Nelson, 2016; Myers, Mackintosh & Goin-Kochel, 2009). Combinations of these challenging and often unpredictable behaviours have led to many parents adopting a hypervigilant parenting style (Woodgate, Ateah, & Secco, 2008). Some parents have described the experience as “...almost like a home with an alcoholic...you are walking on eggshells 24 hours a day” (Woodgate, Ateah, & Secco, 2008, p.1079) and “flight or fight 100% of the time” (Stewart et al., 2016, p.6).

Parents of children with ASD experience higher levels of parenting stress than parents of neurotypical children and children with other disabilities such as Down syndrome, cerebral palsy and intellectual disability (Hayes & Watson, 2013). Meta-analytic studies have also identified that 31% of parents of children with ASD are likely to meet criteria for a diagnosis

of a depressive disorder, and 34% a diagnosis of an anxiety disorder (Schnabel et al., 2019). Three studies to date have hypothesised that the elevated psychological distress observed in some parents of children with ASD could be conceptualised as traumatic stress. In a retrospective study examining symptoms of post-traumatic stress disorder (PTSD) in 265 parents of children with autism, Casey and colleagues (2012) found that 20% of this sample reported experiencing moderate to high levels of post-traumatic stress symptoms in the context of receiving their child's diagnosis of ASD (parents were instructed to consider this as the trigger event when completing the survey). Analyses revealed that 15.5% of parents indicated elevated levels of hyperarousal symptoms in relation to the moment of receiving their child's diagnosis of ASD (Casey et al., 2012).

A diagnosis of PTSD is made on consideration of symptoms in four clusters: intrusive symptoms (i.e. dreams, flashbacks), avoidance of stimuli associated with traumatic events (such as external reminders or distressing memories), negative alterations in cognition and mood (i.e. persistent negative beliefs and negative emotional state), and alterations in arousal and reactivity (i.e. hypervigilance, exaggerated startle response). While parents of children with ASD would be unlikely to be able to avoid external reminders associated with traumatic events if their child is associated with these events, they may engage in avoidance of thoughts and emotions associated with these events.

PTSD is unique among psychiatric diagnoses in that its diagnosis is contingent on an individual being exposed to a specific aetiological event as defined by the DSM-5 (Rosen, 2004). Criterion A of PTSD specifies that an individual have been exposed to "actual or threatened death, serious injury, or sexual violence" (APA, 2013, p.271). Individuals can be

directly exposed to these kinds of events, witness them happen to another, learn of them happening to someone close to them, or repeated exposure to details of traumatic events, as in workers in emergency services (APA, 2013). Receiving a diagnosis of a neurodevelopmental disorder is not considered a Criterion A traumatic event as per the DSM-5 conceptualisation of PTSD. However, some challenging behaviours exhibited by children with ASD may satisfy Criterion A as they carry a threat to life (i.e. suicidal behaviour), or serious injury toward themselves (i.e. self-harming behaviour such as head-banging) or another (i.e. physically harming their caregiver during a meltdown). Furthermore, while Criterion A for PTSD refers to a singular event, parents of children with ASD are more likely to be exposed to multiple, recurring traumatic stressors, as challenging behaviours are generally seen to be chronic for up to 77% of children with ASD (Matson, Mahan, Hess, Fodstad, & Neal, 2010; Richards, Moss, Nelson, & Oliver, 2016).

In a qualitative study by Stewart and colleagues (2016) exploring the experience of parenting stress in a sample of twelve mothers of children with ASD, all participants reported trauma-related symptomatology in the context of their parenting experience. Five of these mothers also spontaneously reported events that could be conceptualised as traumatic stressors that met Criterion A for a PTSD diagnosis, and had distressing and intrusive memories of these experiences. These mothers spoke of having to physically restrain their child to protect them from injuring themselves, a sibling or the parent: “I used to restrain [him] because it just got to the point where I was getting dislocated shoulders and...you know, he was trying to bite chunks out of me” and “between three or four hours I’d have to restrain [him] or he would beat the crap out of me” (Stewart et al., 2016, p.215). Others

described serious injuries resulting from this restraint: “[he] had the biggest tantrum and was near a glass panel and I thought he was going to put his foot through it, so I had to move him, and in the process he broke one of my ribs” (Stewart et al., 2016, p.215).

A third study has examined the presence of post-traumatic stress symptoms in parents of children with ASD through self-report measures. In a sample of 226 parents of children with ASD, Stewart et al. (2020) found that, after controlling for previous exposure to traumatic events, 28.6% of the variance in self-reported trauma symptomatology was explained by being a parent of a child with ASD. Eighteen percent of the sample reported trauma symptomatology indicative of a need for further assessment, having met necessary DSM-5 diagnostic criteria according to a validated symptom checklist (American Psychiatric Association, 2013). The authors considered that challenging behaviours in children with ASD may be a possible precursor to traumatic stress, if such behaviours involved exposure to threat to life or a serious injury. Indeed, of the 18% of participants who did meet the clinical threshold for a provisional diagnosis of PTSD, all reported challenging child behaviours that could potentially be considered traumatic stressors. These behaviours included threatened death or serious injury, such as head-banging, self-hitting/biting, verbal suicidal ideation and physically aggressive behaviour towards others. These challenging behaviours significantly predicted higher PTSD symptomatology, accounting for 30.4% of the variance in PCL-5 scores for parents of children with ASD (Stewart et al., 2020).

In other research examining the physiological profiles of stress in parents of children with ASD, similarities between this population and populations with confirmed PTSD have been noted. Compared to parents of neurotypical children, Seltzer et al. (2010) reported low

levels of cortisol in mothers of adolescents and adults with ASD, and Foody et al. (2015) found lower cortisol levels in both mothers and fathers of children with ASD. Seltzer et al. (2010) also reported that the mothers' cortisol levels remained low even after controlling for maternal age, prescription medication usage, and saliva collection time. Lower levels of cortisol are associated with chronic stress, with this paradoxical suppression of cortisol conceptualized as a symptom of over-activation of the limbic-hypothalamic-pituitary-adrenocortical axis responsible for cortisol regulation (Gunnar & Vasquez, 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 can lead to a sense of physiological burnout that results in this observed hypocortisolism (Gunnar & Vasquez, 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., 2015). These low cortisol levels found amongst parents of children with ASD are comparable to the levels documented in combat soldiers, Holocaust survivors, and individuals diagnosed with PTSD (Heim, Ehler, & Hellhammer, 2000; Yehuda, Boisoneau, & Giller, 1995).

We are yet to see direct evidence of trauma-based psychopathology in the ASD-parent population due to a reliance on self-report measures which can only speak to trauma-based symptomatology. The presence of traumatic stress symptoms described in these studies may be confounded by the use of self-report measures, which tend to overestimate PTSD symptoms and prevalence (Cabizuca et al., 2009; Jones et al., 2006). While self-reported symptoms of PTSD have been identified in previous studies, it remains unclear as to whether

these symptoms are organised around traumatic events. It also remains unclear as to whether they are more reflective of depressive/anxious symptoms (of which parents of children with ASD appear at a greater risk) that overlap with symptoms of PTSD, such as negative mood changes, irritability, anhedonia, avoidance (i.e., panic disorder and agoraphobia) and concentration/sleep disturbances.

There is a clear need for the application of gold standard diagnostic interviews to determine the relevance of a trauma-related diagnostic framework. This approach may be more likely to accurately determine whether some parenting experiences are essentially traumatic in nature, that is, if the event carried “exposure to actual or threatened death, serious injury, or sexual violence” (American Psychiatric Association, 2013, p.271), and if these experiences are temporally related to PTSD symptoms. Given that some parents describe experiencing challenging behaviours at a rate that is “unrelenting”, and feeling like “flight or fight all the time” in the context of their parenting experience (Stewart et al., 2016, p.215), it is possible that some parents may not conceptualise their child’s behaviour as traumatic ‘events’ *per se*, but rather, regular and repeated occurrences that might be normalized as the parenting experience. Therefore, they may not report or articulate them when asked to report traumatic events. Clinical judgement is also called for in disentangling the relevance of possible PTSD symptoms; especially in a population with significantly elevated levels of depression, stress and anxiety.

The present study used a structured diagnostic clinical interview to determine if elevated levels of stress in a population of parents of children with ASD could be validly conceptualised as stemming from event(s) encountered in the parenting experience and the

alignment of these experiences with DSM-5 criterion A traumatic stressors. Detailed information from the diagnostic interview of each case will be explored in this paper to better understand how parenting a child with ASD may involve exposure to traumatic events and how the psychological ramifications of this can be understood from within a trauma framework. Given the high prevalence of challenging behaviours in children with ASD, and previous findings of possible PTSD diagnoses occurring concurrently with these behaviours, we sought to identify any cases of clinical PTSD within this population that were associated with traumatic events related to their child's challenging behaviours.

Method

Participants and Procedure

The sample comprised parents of children with ASD who had participated in a prior study (Stewart et al., 2020) and had consented to be followed up for phone interviews. Participants in the prior study were recruited through social media, online ASD forums, ASD support groups and ASD-relevant non-government organizations.

In total, 124 parents were invited to participate in the study. Of these, 30 agreed to participate and completed phone interviews with the first author. These interviews entailed completion of two structured clinical interviews: the Clinician-Administered PTSD Scale for DSM-5, Past Month Version (CAPS-5; Weathers, Blake, Schnurr, Kaloupek, Marx & Keane, 2015) to assess for diagnoses of PTSD in the course of the participants' parenting experience, and the Mini International Neuropsychiatric Interview (M.I.N.I.; Sheehan et al., 1998), to

assess for prevalence of other psychiatric diagnoses and PTSD beyond the parenting experience.

The final sample consisted of 30 mothers of children with ASD, with a mean age of 42.97 ($SD = 5.82$), who had a child with ASD (23 male and 7 female) with a mean age of 12.43 ($SD = 3.15$). Four fathers were invited to participate in the study but did not respond to the invitation. The average age of participants' children receiving the ASD diagnosis was five years of age ($SD = 2.82$). The participants lived in Australia ($n = 25$), the United Kingdom ($n = 1$), the United States of America ($n = 3$) and Canada ($n = 1$). Parents were asked to identify the type of registered health professional who provided the ASD diagnosis, and the name of the child's specific diagnosis. Diagnoses reported included autism (43.3%), Asperger's syndrome (30%), high functioning autism (6.7%), and PDD-NOS (20%). ASD diagnoses were not independently verified by the research team; however, there is evidence to suggest high concordance between parent-reported ASD diagnoses and clinician-verified diagnoses (Daniels et al., 2011; Warnell et al., 2015).

Approval to conduct the study was granted by the Deakin University Human Research Ethics Committee. Informed consent was given verbally on the phone after participants had read the plain language statement. Interviews were conducted over the phone by a provisional psychologist (AS) who was trained in administration of the materials by a registered clinical psychologist (MS). Interviews took approximately one hour on average to complete and were audio recorded with the participants consent. Each participant was allocated a unique code to label these recordings, which were stored separately from all other data to ensure confidentiality.

Measures

The Clinician-Administered PTSD Scale for DSM-5, Past Month Version (CAPS-5; Weathers, Blake, Schnurr, Kaloupek, Marx & Keane, 2015) is a structured clinical interview instrument used for the diagnosis of post-traumatic stress disorder in civilian groups. The CAPS utilises a 5-point severity rating for each symptom of PTSD (0 = *absent*, 1 = *mild/subthreshold*, 2 = *moderate/threshold*, 3 = *severe/markedly elevated*, 4 = *extreme/incapacitating*) based on a combination of the frequency (how often in the past month) and intensity (minimal, clearly present, pronounced and extreme) of the symptom; only symptoms rated as moderate/threshold (2) or above can be counted toward a PTSD diagnosis. The relatedness of each symptom of PTSD to index traumatic events was carefully scrutinised, for example, with hypervigilant and startle response symptoms only included when they clearly related to index traumatic events rather than general experiences of parenting hypervigilance that have been documented in this population (Stewart et al., 2016). The CAPS, considered the “gold standard” measure in the assessment of PTSD has been demonstrated to have good validity, test-retest reliability and inter-rater reliability and sensitivity to clinical change (Weathers, Keane & Davidson, 2001). When invited to consider a Criterion A event, participants were instructed to think of the most stressful event that had occurred in the context of parenting their child with ASD. This event was then assessed for the type of traumatic exposure (experienced, witnessed, learned about or exposed to aversive details) and if the event carried a threat to life, serious injury or sexual violence.

The Mini International Neuropsychiatric Interview (M.I.N.I.; Sheehan et al., 1998) is a structured clinical interview instrument used for the diagnosis of seventeen categories of

DSM-5 psychiatric disorders. For the present study, the M.I.N.I was not used in full; rather, relevant possible diagnoses were assessed for based on existing literature which suggests their greater prevalence in parents of children with ASD. The M.I.N.I was used to assess for the following relevant diagnoses: major depressive disorder, panic disorder, agoraphobia, generalised anxiety disorder, social anxiety disorder, post-traumatic stress disorder (beyond the context of their experience in parenting their child with ASD) and alcohol use disorder. Medical, organic or drug causes for any of the above disorders were also ruled out.

The M.I.N.I has demonstrated good validity, test-retest reliability and inter-rater reliability when compared to other, well-established structured diagnostic interviews, including the Composite International Diagnostic Interview (Lecrubier et al., 1997) and the Structured Clinical Interview for DSM-III-R (Sheehan et al., 1997).

Results

Inter-rater reliability

The second author, a registered clinical psychologist, listened to the recordings of interviews with six randomly chosen participants, and assessed them on the M.I.N.I and categorical PTSD diagnosis while blinded to the initial raters' diagnoses. There was 100% agreement for diagnoses on these six cases.

Psychiatric diagnoses

Frequencies of psychiatric diagnoses are reported in Table 1.

TABLE 1 HERE

Three participants met criteria for a diagnosis of PTSD in the context of family violence perpetrated by their spouse (as identified using the M.I.N.I.). These three participants also met criteria for a diagnosis of PTSD in the context of their parenting experience (as measured by the CAPS-5). Given it would not be possible to definitively separate the influence of these two separate traumatic stressors, they were excluded from subsequent analyses using their CAPS-5 data. Given the focus of this study, clear alignment between the relevant Criterion A events related to parenting experience and the subsequent PTSD symptomatology is critical, hence the conservative approach to case inclusion in the final results. Of the remaining 27 participants, six met criteria for PTSD in the context of parenting their child (22.2%) as assessed by the CAPS-5. Beyond these six participants, and the three participants who met criteria for PTSD in the context of family violence, a further nine parents met Criterion A for PTSD. Of these nine parents, only three identified any further symptoms of PTSD, and did not endorse enough criteria for diagnosis.

PTSD in the context of parenting a child with ASD

Specific incidents occurring in the course of parenting the child with ASD were determined to be Criterion A traumatic stressors through establishing a temporal sequence between the events and the ensuing B-E symptoms. Each symptom was investigated for its relatedness to the traumatic event and only included as a symptom if it clearly related to the

traumatic event in the sense of starting after the event, or becoming significantly worse after the event.

The specific incidents linked with the PTSD diagnosis are now discussed. Three participants had experienced a threat to their life when their child was physically violent towards them. Two participants reported witnessing a threat to the life of their child in the context of suicidal ideation and behaviours. One parent reported witnessing a threat to the life of her child's father when their child was physically violent towards him. Brief summaries of the experiences of those participants who met criteria for PTSD in the course of their parenting experience are described below. Further detail regarding the number of symptoms described by participants in each symptom cluster of PTSD is provided in Table 2 below.

Sarah* is a 42-year-old mother of a 12-year-old boy with ASD; she reported a fear for her life in the context of being physically attacked by her son Liam*. Since he was 3-years-old, Liam had been physically violent toward Sarah in the form of biting, kicking, punching, pulling her hair out and strangling her. On the M.I.N.I, Sarah met criteria for comorbid diagnoses of (1) major depressive disorder, recurrent, (2) panic disorder and (3) generalised anxiety disorder.

Jane* is a 55-year-old mother to Melissa*, a 12-year-old girl with ASD. Jane reported that her daughter attacked her husband Steven* on a near nightly basis in the context of meltdowns for the past two years, occurring usually after being told to stop using her tablet device. Jane reported that while Steven restrained Melissa during meltdowns, he would sustain numerous bruises and bites, and that Melissa had threatened to stab him with a kitchen knife on one specific occasion where the police had to be called to restrain Melissa.

On the M.I.N.I, Jane met criteria for comorbid diagnoses of (1) major depressive disorder, recurrent and (2) generalised anxiety disorder.

Andrea* is 47-year-old mother to Michael*, an 11-year-old boy with ASD. Andrea reported witnessing a threat to the life of her son in the context of suicidal ideation and behaviours. Over the past three years, she noted that Michael had expressed verbal wishes to die, sharing his overt plans to suicide with her, saying “I wish I was dead or was never born”. Andrea described having to “talk him down” from acting on suicidal ideation on a daily basis in the past month, reporting genuine fear that he would suicide in the context of a particularly difficult time at school. On the M.I.N.I, Andrea met criteria for comorbid diagnoses of (1) major depressive disorder, recurrent, (2) alcohol use disorder, mild severity and (3) generalised anxiety disorder.

Belinda* is a 44-year-old mother of a 16-year-old boy with ASD; she reported experiencing a perceived threat to her life in the context of physical violence from her son Jacob*, who would “get angry and lash out...by hitting me”. Belinda noted that Jacob had been physically violent towards herself and his two younger siblings since the age of twelve during episodes of anger and distress. On the M.I.N.I, Belinda met criteria for a comorbid diagnosis of major depressive disorder, recurrent.

Tahlia* is a 48-year-old mother to Max*, a 15-year-old boy. She reported experiencing a perceived threat to her life in the context of physical violence from Max approximately once a fortnight. Tahlia indicated that she was “scared for my life when alone with him” as Max “becomes aggressive, threatens us, tries to choke me”. On the M.I.N.I,

Tahlia met criteria for comorbid diagnoses of (1) major depressive disorder, recurrent and (2) panic disorder.

Jen* is a 42-year-old mother to Paul*, a 17-year-old boy with ASD. She reported witnessing a threat to the life of Paul in the context of suicidal ideation and behaviours. Two years ago, he had held a knife to his throat and expressed a wish to suicide, saying that “he didn’t have anything good in his life”. Jen expressed ongoing fears that he would suicide in the context of ongoing low mood since this episode. On the M.I.N.I, Jen met criteria for comorbid diagnoses of (1) major depressive disorder, recurrent and (2) agoraphobia.

TABLE 2 HERE

Repeated nature of traumatic events

A key finding of these interviews was the repeated nature of these parents’ experiences with traumatic events in the context of parenting their child with ASD. Of the six cases detailed above, all identified traumatizing parenting events as occurring repeatedly over time, rather than just as a singular event. Although some parents were able to identify the “worst” event, each had experienced lesser and more chronic versions of that event since. For example, the third case described above (a 47-year-old mother of a 11-year-old boy) reported having to intervene with her son’s verbal suicidal ideation daily, which could be considered a traumatic stressor if these daily suicidal ideations represented a serious and genuine threat to his life. Three parents spontaneously indicated difficulty in identifying just one singular

event: “It wasn’t just one event”, “It was happening every night” and “It’s not just that one particular event”.

Discussion

The aim of the present study was to validate the applicability of a trauma-related diagnostic framework to elevated stress in parents of children with ASD. Thirty mothers of children with ASD were interviewed using a gold standard diagnostic interview for PTSD, with a specific focus on the alignment of the PTSD symptomatology with the Criterion A parenting experience. Three participants were excluded as they met diagnostic criteria for PTSD stemming from experiences beyond parenting their child with ASD. Of the remaining 27 participants, six (22.2%) met diagnostic criteria for post-traumatic stress disorder arising in the context of their parenting experience. The Criterion A traumatic stressors identified were related to challenging child behaviours of physical violence toward caregivers, as well as suicidal ideation and behaviours.

These findings are the first to provide diagnostic evidence of PTSD in parents of children with ASD relating to Criterion A traumatic stressors specific to parenting a child with ASD. They build on the findings of previous studies, which speculated on the possibility of elevated psychological distress in some parents of children with ASD being more validly conceptualised as traumatic stress, where elevated psychological distress occurred in the context of challenging child behaviours of a traumatic nature. In a previous study on this topic, challenging child behaviours accounted for 30.4% of the variance in self-reported PTSD symptoms in parents of children with ASD when exposure to other traumatic life

events were controlled for (Stewart et al., 2020). Disruptive-antisocial behaviours and anxiety behaviours were significantly predictive of PTSD symptoms, with these domains reflecting behaviours that could represent Criterion A traumatic stressors, such as head banging, suicidal ideation, kicking/hitting others, poor sense of danger, hitting/biting self and deliberately eloping (Stewart et al., 2020). It appears that where challenging behaviours are more frequent and/or severe, parent distress is more likely to be elevated. Our conceptualisation that, where challenging behaviours could represent Criterion A traumatic stressors as per DSM-5, parents may experience a traumatic stress response to these behaviours, was supported. The present findings provide strong evidence for a causal association between challenging child behaviours and subsequent parental symptoms of PTSD. This was achieved by establishing temporal precedence between such behaviours and symptoms through diagnostic interviewing.

An important finding of these interviews was the repeated nature of traumatic stressors reported by parents. As one mother eloquently stated: “it’s happening frequently enough that I don’t have time to flashback...it happens every day”. Of the six participants who met criteria for PTSD diagnoses, all identified numerous index events related to challenging child behaviours, and smaller daily challenges stemming from these. This presented difficulty in conceptualising the relatedness of each DSM-5 symptom of PTSD to a singular index event as required for a PTSD diagnosis within DSM-5. This raises the issue of complexity of interventions for traumatic stress symptoms in the context of ongoing potentially traumatic exposures. Many PTSD interventions are focused on past events;

therefore, therapeutic interventions for parents of children with ASD that present with ongoing challenging behaviours must be adapted to reflect the ongoing parenting context.

A challenge in assessing for PTSD in participants of this study arose from judging the relatedness of each symptom to index traumatic stressors. Almost every participant identified what could be described as clinically-significant startle responses and levels of hypervigilance as part of their experience of parenting a child with ASD. For example, needing to be constantly on guard for stimuli that could cause a meltdown, or constantly monitoring their child's whereabouts and mood, and jumping at the slightest noises that may indicate an oncoming meltdown. The relatedness of each symptom of PTSD to index traumatic events was carefully scrutinised in the present study, with symptoms only included when they clearly related to index traumatic events (i.e. startling that was interpreted as being in response to the child possibly engaging in self-injurious behaviours). The issue of a high prevalence of traumatic stress symptoms in this population represents a significant challenge in clinical settings. Given the frequency and ubiquity of such symptoms, they may go unreported by parents or overlooked by clinicians, who may both perceive such reactions as a normal or expected part of their parenting experience. Although this may certainly be true of some parents (indeed, 15.5% of parents identified hyperarousal symptoms stemming from the moment of receiving their child's diagnosis [Casey et al., 2012]), it is necessary to investigate for PTSD where these symptoms occur in tandem with traumatic events involving a threat to life or serious injury.

The most notable limitation identified in this study is the issue of psychiatric comorbidity. Of the six participants who met criteria for PTSD in the context of their

parenting experience, all met diagnostic criteria for at least one comorbid psychiatric disorder as measured by the M.I.N.I. All six participants met the criteria for major depressive disorder, recurrent. Two participants met criteria for panic disorder, one met criteria for agoraphobia and two met criteria for generalised anxiety disorder. One participant also met criteria for a diagnosis of alcohol use disorder, mild severity. This is however consistent with the literature identifying very high rates of comorbidity between PTSD and depression across trauma exposed populations (Chapman et al., 2012). While significant effort was made to determine the relatedness of each PTSD symptom to the traumatic event identified by the participant, and anticipating the presence of psychiatric comorbidity in the sample, it was not clinically or empirically possible to accurately allocate symptoms differentially to the varying comorbidities. This represents a challenge for clinicians working with parents of children with ASD, who must attempt to differentiate PTSD from psychiatric comorbidities such as mood and anxiety disorders.

The nature and size of the sample are a further limitation of the present study. The rate of PTSD identified in this study cannot be considered a representation of the PTSD prevalence in this population, due to the small sample size and issues of sample representativeness. Due to the limited sample size and limited demographic data available, it was not possible to conduct population comparisons, which may limit the generalisability of the present results. The current sample cannot be described as representative of the population of parents of children with ASD as it assessed mothers only. Women have a two to three times higher risk of developing PTSD than men (Olf, 2017), and women may report greater dissociative symptoms, and more acute symptoms than men (Irish et al., 2011).

Participants also self-selected into the study, and only 30 parents of a total 124 invited chose to participate. This may suggest something non-representative about the sample, such as reduced time pressures, or a greater level of psychological resilience that would engender them to talk about “the worst event” they had experienced while parenting their child. Our sample draws from four Western countries (Australia, USA, Canada and UK), and differences may exist between the countries with regards to ASD and mental health support service availability and affordability. Support service access both for parents and children has been implicated in the maintenance of parent distress, with difficulty accessing appropriate services implicated in greater levels of stress (Boshoff, Gibbs, Phillips, Wiles, & Porter, 2016) and poorer coping abilities (Cain Spannagel, 2012). It may be that some of the differences in PTSD symptoms in the current sample can be attributed to differences between mental health service accessibility in the countries of origin of participants.

Despite these limitations, the present study has several strengths, including the use of a gold standard diagnostic interview for PTSD to establish temporal precedence between traumatic stressors in the form of challenging child behaviours, and subsequent parent symptoms. Future research using diagnostic interviews to assess for PTSD in this population would benefit from measurement of possible mediating, moderating or protective factors for PTSD in this population. Given that approximately three quarters of the population may be exposed to a traumatic event in their lifetime (Phoenix Australia, 2013) yet only approximately 4.4% will develop PTSD in response to such an event (McEvoy, Grove & Slade, 2011), it is acknowledged that not all parents of children with ASD will develop PTSD from exposure to challenging child behaviours that are traumatic in nature. It was not clear

from the present data why some parents developed PTSD while others did not. It is possible to speculate about factors known to be associated with the development of PTSD, such as the severity of the traumatic event, the level of support received after the event, and aspects of individual coping after the event such as rumination or dissociation (Santiago et al., 2013). Future research is essential to determine the factors that may predict, or prove protective of, PTSD developing in parents of children with ASD exposed to traumatic challenging behaviours. This study indicates the need for a larger epidemiological study that can recruit a more representative sample (including fathers) to more accurately estimate the prevalence of PTSD in this population, and explore the relationship between challenging child behaviours and PTSD diagnoses. There may be specific factors associated with ASD (i.e. comorbid cognitive impairment, reduced access to ASD-specific support services) that may be relevant to the aetiology of PTSD in parents of children with ASD.

To our knowledge, this is the first study to validate a PTSD-based diagnostic framework in a sample of parents of children with ASD. Results indicate that a significant minority of parents meet criteria for a diagnosis of PTSD in the context of their parenting experience, stemming from traumatic events of challenging behaviours of their child, including physical violence toward the parent, self-injurious or suicidal behaviours. These events were not singular in nature; indeed, for some parents, they occurred on a daily or near-daily basis. No parent identified a single index event with no subsequent related events.

These results have significant implications for practitioners engaged with parents of children with ASD, as the need to differentiate between symptoms of depression and anxiety and symptoms of PTSD is indicated where the parent is exposed to challenging behaviours

that may be traumatic in nature. Where symptoms of PTSD are indicated in a parent of a child with ASD, practitioners should consider the temporal connections between such symptoms and any traumatic events that may have occurred in the context of parenting their child. Given the high frequency of many of these behaviours, it may be necessary to identify those events where a threat to life or serious injury were involved. The presence of PTSD in parents has significant implications for the parent-child relationship, including poorer parental functioning (Zerach et al., 2012), greater conflict with children (Ruscio et al., 2002) and greater severity of discipline (Cohen, Hien & Batchelder, 2008). Further, a relationship between parental PTSD and challenging child behaviours has also been documented in the other direction, with greater parental PTSD symptoms predicting greater child distress and behavioural problems (Lambert, Holzer, & Hasbun, 2014). This potential bidirectional relationship indicates the need for urgent attention from health professionals and researchers to further explore and address the presence and aetiology of PTSD in some parents of children with ASD, who experience multiple, even daily traumatic events in the context of their parenting experience. The complex PTSD framework, which refers to the experiences of individuals exposed to chronic trauma, generally of an interpersonal nature (i.e. childhood abuse), may be useful in conceptualising the experiences of parents of children with ASD who are exposed to ongoing traumatic stressors in the course of parenting (Cloitre, Garvert, Brewin, Bryant, & Maercker, 2013). The focus of complex PTSD on relational disturbances stemming from chronic exposure to trauma may be of particular relevance in supporting parents, in the task of continuing to parent their child in the face of ongoing exposure.

The implications extend from the need for clinicians and practitioners to actively screen for symptoms of PTSD in parents in addition to other psychiatric morbidities, and to also consider interventions directed at the PTSD phenomena. Further research should also explore the nature and type of interventions for parents with PTSD in the context of these experiences; namely, how gold standard first line interventions for PTSD may be adapted and targeted in the context of such parenting exposures and also incorporate the issues of continued exposure, threat and risk in this population.

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Table 1

Frequency of Psychiatric Diagnoses as Measured by the M.I.N.I (N = 30)

Diagnosis	Frequency	Percent
Major Depressive Disorder	21	70.0%
Panic Disorder	4	13.0%
Agoraphobia	3	10.0%
Generalised Anxiety Disorder	7	23.3%
Social Anxiety Disorder	2	6.7%
Alcohol Use Disorder	5	16.7%

Table 2

Number of PTSD Symptoms Reported by Participants, Arranged By Symptom Cluster

Participant	PTSD Symptom Clusters			
	Re-experiencing (B – max*. 5)	Avoidance (C – max. 2)	Cognition & mood (D – max. 7)	Arousal & reactivity (E – max. 6)
Sarah	1	2	5	2
Jane	3	1	3	1
Andrea	3	1	5	4
Belinda	2	1	2	3
Tahlia	3	1	3	2
Jen	3	1	6	2

*Max = maximum number of symptoms in this cluster. Note: a minimum of one symptom each from Clusters B and C, and two symptoms each from Clusters D and E, is required for a diagnosis of PTSD.