Traumatic stress in parents of children with autism spectrum disorder

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List of peer-reviewed publications and presentations


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Abstract

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental disorder that has no clear aetiology, cure or standard medical treatment. Behaviours associated with the ASD phenotype, as well as other challenging externalising behaviours exhibited by some children with ASD, are known to increase the experience of stress in parents. Examples of these behaviours include aggression, elopement, self-injurious behaviours and, although atypical, suicidal ideation and attempts. Constellations of these challenging and dangerous behaviours can be of an ongoing nature, and present in children irrespective of ASD severity or co-morbid intellectual impairment. It was hypothesised that some of these behaviours could place the child and/or parent at risk of threatened or actual serious injury, and in a small percentage of cases, threatened or actual death. The aim of this thesis was to investigate the validity of adopting a traumatic stress framework for understanding the parenting stress experienced by some parents of children with ASD.

Paper 1 is a review article which details the research evidence for the psychological impact of parenting a child with ASD who exhibits challenging behaviours (Stewart, McGillivray, Forbes, & Austin, 2016; Chapter 4). Depression, anxiety, and stress were frequently reported throughout the literature; however, only one paper was identified that explored the notion of posttraumatic stress symptoms (PTSS). Two other studies of interest that contribute to this emerging area of research adopted physiological approaches, reporting cortisol profiles in parents of children with ASD were similar to those of individuals with PTSD. The negative implications of trauma symptomatology were discussed and the need for further research identified.
Paper 2 reported findings from the first empirical study presented in this thesis (Stewart, Knight, McGillivray, Forbes, & Austin, in press; Chapter 5). A qualitative design was adopted to explore the validity of using a traumatic stress framework to conceptualise some parenting experiences. Findings were supportive of the concept, with 40% of mothers spontaneously reporting events that constituted traumatic stressors as well as the presence of other PTSD diagnostic criteria. The findings supported the face and ecological validity of the traumatic stress perspective amongst this population; however, the findings warranted confirmation via a larger quantitative study.

The final paper in this thesis, Paper 3, reported findings from the second empirical study (Stewart, McGillivray, Forbes, Mohebbi, & Austin, manuscript submitted; Chapter 6). The study was designed to address the limitations of the qualitative study (e.g., small sample size, social influence, lack of control group) and to explore the rate of PTSD symptomatology in parents of children with ASD. The predictive relationship between challenging behaviours in children with ASD and parent reports of PTSD symptomatology were also explored. Hypotheses were confirmed as parents of children with ASD endorsed higher rates of PTSD symptomatology in comparison to parents of typically developing children, and the frequency of challenging behaviours predicted PTSD symptom severity in parents. Formal clinical assessments were not conducted with the participants and, therefore, clinical outcomes were not identified, however, the PTSD measure used enables “possible caseness” to be identified through reference to normative samples. The results of these comparisons revealed 18.58% of parents of children with ASD and 0% of parents of children with typically developing children reported symptoms consistent with consideration of a provisional DSM-5 PTSD diagnosis.
Chapter 1: Autism Spectrum Disorders

1.1 Overview

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental disorder that has no clear aetiology, cure, or standard medical treatment (Woodgate, Ateah, & Secco, 2008). It is a life-long and often debilitating condition that is typically diagnosed during the first few years of life (Kozlowski, Matson, & Rieske, 2012). ASD is characterised by impairments in social communication and interaction across multiple contexts, as well as restricted, repetitive patterns of behaviour or interests (American Psychiatric Association [APA], 2013). Symptomatology presents in the early developmental period (although may not fully manifest until social demands exceed limited capacities) and causes impairment in social, occupational, and other important areas of functioning (APA, 2013). Manifestations of ASD vary greatly depending on the severity of the symptomatology, developmental level, and chronological age (APA, 2013). In the most recent edition of the Diagnostic and Statistical Manual of Mental Health Disorders (DSM-5; APA, 2013), the term "autism spectrum disorder" was introduced to encompass what once were differential diagnoses of autism, pervasive developmental disorder not otherwise specified, and Asperger’s disorder. In Australian children aged 0-14 years, ASD is the fifth leading cause of burden of disease’ and represents the second leading ‘burden of disease’ in males and the eighth in females (Begg et al., 2007). ‘Burden of disease’ is defined in terms of fatal burden (i.e., years of life lost) and impact on functional capacity (i.e., years lived with disability) (Australian Institute of Health and Welfare, 2009).
1.2 Diagnosis

Diagnostic and Statistical Manual of Mental Disorders

*Autism: the term autism* was first introduced in 1909 by a Swiss psychiatrist, Ernst Bleuler, who used the term to describe the behavioural characteristics of patients with schizophrenia. He noted the marked withdrawal in patients, as well as association loosening, ambivalence, and affect inappropriateness. Autism was a primary descriptor of schizophrenia that referred to the behaviour of retreating into a self-contained existence filled with delusions and hallucinations (Benaron, 2009). It was in this context that the word autism appeared in the 1st and 2nd edition of the DSM (APA, 1952, APA, 1968) under the diagnostic entity ‘schizophrenia, childhood onset’.

In 1943, Leo Kanner, an Austrian pioneer in the field of child psychiatry, published a seminal paper titled ‘autistic disturbances of affect contact’ (Kanner, 1943). Kanner described behavioural characteristics of 11 children (eight males, three females) who presented with disturbances of affective contact, communication deficits, a lack of engagement with others, and bizarre interactions with inanimate objects. Most of these children were also described as rigid and inflexible, requiring routine and sameness in their environment. Unlike Bleuler, Kanner emphasised the failure to develop relationships as opposed to withdrawal from relationships seen in patients with schizophrenia (Rutter, 1978). Kanner termed this unidentified syndrome *early infantile autism*. Early infantile autism was included in the 3rd edition of the DSM (DSM-III; APA, 1980) as a discrete clinical disorder. The disorder encompassed a ‘triad of impairments’ which referred to gross deficits in social interaction, language development, and bizarre and/or repetitive behaviours (APA, 1980). Other diagnostic criteria included the onset of symptomatology prior to 30
months of age, a pervasive lack of responsiveness to people, and the absence of
delusions, hallucinations, loosening of associations, and incoherence associated with
schizophrenia (APA, 1980).

Several years later, substantial revisions were made and the DSM-III-R was
published (APA, 1987) which saw early infantile autism renamed ‘Autistic disorder.’
The diagnostic criteria in the DSM-III-R broadened, detailing 16 items, which were
clustered under three headings: social interaction, social communication, and
activities and interests (see Table 1). In the 4th edition of the DSM (DSM-IV) and
subsequent revision (DSM-IV-TR), the description of autistic disorder remained
relatively unchanged, with the exception of fewer criteria required for diagnosis (see
Table 2).
Table 1

*Diagnostic criteria for Autistic Disorder (DSM-III-R, 1987) (299.00)*

At least eight of the following sixteen items are present, these to include at least two items from A, one from B, and one from C.

Note: Consider a criterion to be met only if the behaviour is abnormal for the person's developmental level.

A. Qualitative impairment in reciprocal social interaction as manifested by the following:
   1. Marked lack of awareness of the existence or feelings of others.
   2. No or abnormal seeking of comfort at times of distress.
   3. No or impaired imitation.
   4. No or abnormal social play.
   5. Gross impairment in ability to make peer friendships.

B. Qualitative impairment in verbal and nonverbal communication, and in imaginative activity, as manifested by the following:
   1. No mode of communication, such as communicative babbling, facial expression, gesture, mime, or spoken language.
   2. Markedly abnormal nonverbal communication, as in the use of eye-to-eye gaze, facial expression, body posture, or gestures to initiate or modulate social interaction.
   3. Absence of imaginative activity, such as playacting of adult roles, fantasy characters, or animals; lack of interest in stories about imaginary events.
   4. Marked abnormalities in the production of speech, including volume, pitch, stress, rate, rhythm, and intonation.
   5. Marked abnormalities in the form or content of speech, including stereotyped and repetitive use of speech; use of "you" when "I" is meant; idiosyncratic use of words or phrases; or frequent irrelevant remarks.
   6. Marked impairment in the ability to initiate or sustain a conversation with others, despite adequate speech.

C. Markedly restricted repertoire of activities and interests, as manifested by the following:
   1. Stereotyped body movements, e.g., hand-flicking or twisting, spinning, head-banging, complex whole-body movements.
   2. Persistent preoccupation with parts of objects.
   3. Marked distress over changes in trivial aspects of environment.
   4. Unreasonable insistence on following routines in precise detail.
   5. Markedly restricted range of interests and a preoccupation with one narrow interest.

D. Onset during infancy or childhood. Specify if childhood onset (after 36 months of age).

Specify: is childhood onset (after 36 months of age).
Table 2  
*Diagnostic criteria for Autistic Disorder (DSM-IV, 1994) (299.00)*

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

1. Qualitative impairment in social interaction, as manifested by at least two of the following:
   (a) Marked impairment in the use of multiple nonverbal behavior such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction.
   (b) Failure to develop peer relationships appropriate to developmental level.
   (c) A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people.
   (d) Lack of social or emotional reciprocity.

2. Qualitative impairments in communication as manifested by at least one of the following:
   (a) Delay in or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime).
   (b) In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others.
   (c) Stereotyped and repetitive use of language or idiosyncratic language.
   (d) Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level.

3. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
   (a) Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus.
   (b) Apparently inflexible adherence to specific, non-functional routines or rituals.
   (c) Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements).
   (d) Persistent preoccupation with parts of objects.

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rhett’s Disorder or Childhood Disintegrative Disorder.
Asperger’s Disorder: Hans Asperger, an Austrian-born psychiatrist and paediatrician, unaware of Kanner’s work, published a paper around the same time as Kanner which introduced the term Asperger’s. It detailed his observations of four young boys who engaged in patterns of behaviour he referred to as ‘autistic psychopathology’ (Asperger, 1944). He noted the distinct difficulty with social interactions and the desire of his patients to hold intense and bizarre interests. Unlike Kanner, Asperger believed strong linguistic skills were a prominent feature of autistic psychopathology. Although Asperger published this paper around the same time that Kanner described autism, Asperger’s Disorder was not included in the DSM until the 4th edition (and remained in the revised version of this edition) (APA, 1994, 2000). The significant delay in the inclusion of Asperger’s Disorder in the DSM is thought to be the result of Asperger’s work not being translated into English until 1991 (Frith, 1991). Asperger’s Disorder was differentiated from Autistic Disorder by degree of severity and only two of the ‘triad of impairments’ were required for diagnosis (see Table 3).

Autism Spectrum Disorder: In 2013 the 5th edition of the DSM (DSM-5; APA, 2013) saw the introduction of ‘Autism Spectrum Disorder’ (ASD) which encompassed individual DSM-IV diagnoses of Autistic Disorder, Asperger’s Disorder, Pervasive Developmental Disorder-Not Otherwise Specified, and Childhood Disintegrative Disorder (APA, 2013). The ‘triad of impairments’ structure was revised, with social interaction and communication collapsed into one domain of impairment (see Table 4). Severity specifiers were also introduced to categorise the impact of symptoms on adaptive functioning.
Table 3

*Diagnostic criteria for Asperger’s Disorder (DSM-IV, 1994) (299.80)*

A. Qualitative impairment in social interaction, as manifested by at least two of the following:
1. Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction.
2. Failure to develop peer relationships appropriate to developmental level.
3. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people).
4. Lack of social or emotional reciprocity

B. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
1. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus.
2. Apparently inflexible adherence to specific, non-functional routines or rituals.
3. Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements).
4. Persistent preoccupation with parts of objects.

C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.

D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).

E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.

F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.
Table 4

Diagnostic criteria for Autism Spectrum Disorder (DSM-5, 2013) (299.00)

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history:

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.

2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.

3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

Specify current severity:
- Severity is based on social communication impairments and restricted, repetitive patterns of behaviour.

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history:

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).

3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).

4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Specify current severity:
- Severity is based on social communication impairments and restricted, repetitive patterns of behaviour.

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.
1.3 Prevalence of ASD

ASD prevalence rates have been steadily rising overtime. Prevalence figures from published studies between 1966 to 1993 and 1994 to 2004 rose from 0.05% to 0.13% respectively (Fombonne, 2005). More recent studies indicate that ASD affects approximately 1.47% of the U.S. population (Centres for Disease Control and Prevention, 2014). In Australia, ASD prevalence rates have risen from approximately 0.63% (Williams, MacDermott, Ridley, Glasson, & Wray, 2008) to more recent estimates of approximately 0.8% (Barbaro & Dissanayake, 2010). ASD has been identified as the fastest growing developmental disability in the U.S., with a projected increase in the cost of ASD services from $175-262 billion per year to $200-400 billion per year (Centre for Disease Control and Prevention (n.d.).

At this point in time there is no definitive research that explains the upward trend in prevalence. It is unclear whether the rise represents a genuine increase in incidence or is an artefact of widening of the DSM diagnostic criteria, increased education and awareness, and an increase in service availability (APA, 2013; Fombonne, Zakarian, Bennet, Meg, & McLean-Heywood, 2006). Regardless of the cause of the rise in prevalence, ASD is a growing public health issue, which has implications for current and future needs in services and early intervention.

1.4 Aetiology of ASD

Many theories exist as to the aetiology of ASD and the rising occurrence of this disorder. Two of the most well-known cognitive theories that explain aspects of ASD behaviours include ‘Theory of Mind’ (ToM) and ‘Weak Central Coherence’ (WCC). The ToM hypothesis refers to difficulty in inferring what others are thinking, believing, or desiring, and to use this information to explain and predict
another person’s behaviour (Krahn & Fenton, 2012). This form of ‘mindblindness’ is thought to account for social and communication impairments (Senju, 2012). Although numerous studies report ToM deficits in individuals with ASD when compared to typically developing peers, there is evidence that individuals with higher functioning on the spectrum can demonstrate ToM (Bowler, 1992; Ponnet, Buysse, Roeyers, & De Corte, 2005). The WCC theory posits that individuals with ASD are limited in their ability to see the ‘whole’ picture, instead processing finite detail in a piecemeal way (Rajendran & Mitchell, 2007). This cognitive style is hypothesised to result in a failure to use context to aide in an understanding of the environment (e.g., information from another person’s facial expression, tone of voice, and gestures) (Schroeder, Desrocher, Bedko, & Cappadocia, 2010).

The original view that ASD is a psychogenic disorder is now considered obsolete. For quite some time is has been acknowledged that ASD is at least partially genetic. For example, in a recent meta-analysis of the heritability of ASD, correlations for monozygotic and dizygotic twins were .98 and .53 respectively when the ASD phenotype was set at 5%, which is in line with the Broad Phenotype of ASD. (Tick, Bolton, Happe, Rutte, & Rijsdijk, 2016). For a more comprehensive review of genetics, please see Hens et al.’s (2016) literature review of genetics and autism.

Imagining and post-mortem studies have also implicated the involvement of the cerebellum, limbic system, corpus callosum, fusiform gyrus, and brainstem in the manifestation of ASD (Bauman & Kemper, 2005). For example, abnormalities in the cerebellum are thought to be associated with impairments in joint attention, language and cognitive functioning, as well as the presence of repetitive and restricted behaviours (Schroeder et al., 2010). Despite the ongoing evolution of neurobiological
findings, cognitive theories, and genetic understanding, a common causative factor for ASD remains elusive.

**Gender**

The most widely reported male-female ratio is 4-5:1 (Fombonne, 2003; Fombonne, Quirke, & Hagen, 2011). Even when showing the same level of ASD symptoms, females are less likely to be diagnosed than males, and females who receive an ASD diagnosis are more likely to present with an intellectual or behavioural impairment (Constantino & Charman, 2012). Although no specific genetic, developmental, or environmental factor has been definitively identified to explain the gender discrepancy, it is clear that factors are operating between the time of conception and end of a child’s second year of life, when most ASD diagnoses manifest and the higher prevalence in males if fully apparent (Constantino & Charman, 2016).

1.5 Differential diagnosis and co-morbidity

According to the DSM-5 diagnostic criteria for ASD, the clinician must first eliminate a number of other conditions, specifically; Rhett’s syndrome, selective mutism, language disorders and social communication disorders, intellectual disability without ASD, stereotypic movement disorder, attention deficit hyperactivity disorder and schizophrenia.

ASD is commonly associated with a wide range of intellectual/developmental, psychiatric, medical, and genetic disorders. Co-morbid conditions commonly include intellectual disability, epilepsy, anxiety disorders, mood disorders, obsessive-compulsive traits (e.g., inflexibility and behavioural rigidity),
attention deficit disorder, language disorder, and dyslexia (Attwood, 2007; Frith, 2003).
Chapter 2: Parenting children with ASD

2.1 Autism spectrum disorders and challenging behaviours

In the DSM-5, disruptive and challenging behaviours are reported to be more common in children and adolescents with ASD than other neurodevelopmental disorders, including intellectual disability (APA, 2013). In addition to the core phenotype of ASD, individuals commonly exhibit a range of challenging behaviours. Challenging behaviours have been defined by Emerson (1991) as, “Culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely placed in serious jeopardy, or behaviour which is likely to seriously limit the use of, or result in the person being denied access to, ordinary community facilities.” (Emerson, 1991, p. 3).

Challenging behaviours in individuals with ASD are behaviours that are difficult to manage, may be harmful to people or property, may limit a person’s access to the community, and negatively affect their life and the life of their caregivers (Brylewski & Duggan, 2004). Although not all individuals with ASD will exhibit challenging behaviours, when present, these behaviours have a greater physical and emotional impact on parents than core ASD symptoms (Pearson et al., 2006). Prevalence rates of challenging behaviours for children and adolescents with ASD range from 63.4% to 94% (Jang, Dixon, Tarbox, & Granpeesheh, 2014; Matson, Wilkins, & Macken, 2009; McTiernan, Leader, Healy, & Mannion, 2011; Murphy, Healy, & Leader, 2009). Due to inconsistencies in methodologies, and definitions of both ASD and challenging behaviours, the actual prevalence of various types of challenging behaviours remains unclear (Butrimaviciute & Grieve, 2014). The types of challenging behaviours that are of particular concern include elopement...
behaviours can place the child and parent/others at risk of threatened or actual serious injury, and in a small percentage of cases, threatened or actual death.

2.1.1 Elopement

Elopement is a behaviour that occurs when a child wanders or runs from a specified area without parent permission (Lang et al., 2010), demanding vigilant parenting to ensure child safety. In a community sample of 1,200 children with ASD, parents reported that 49% had eloped; 26% had been missing long enough to cause concern, and of those missing, 24% had been in danger of drowning and 65% in danger of traffic injury (Anderson et al., 2012). Elopement is particularly concerning for parents, given this behaviour is associated with the highest standardised morality rate in children with ASD between the ages of five and ten (5.4%) (Shavelle, Strauss, & Pickett, 2001).

2.1.2 Aggression

Aggressive behaviours are common amongst children with ASD. Research tends to report on the presence of conduct problems (e.g., Lecavalier, Leone, & Wiltz, 2006) which includes pushing, hitting, kicking, and biting others to a moderate/severe degree (Farmer & Aman, 2011). These behaviours can be of the level of severity that results in hospitalisation and/or police involvement (Myers, Mackintosh, & Goin-Kochel, 2009). Prevalence rates of aggressive behaviour amongst ASD populations range from 8% to 68% and variation is posited to be the result of differences in definitions of aggressive behaviours (e.g., verbal aggression...
versus physical aggression), measures used, and sample ascertainment methods (Hill et al., 2014). Results of two large-scale studies involving 1380 and 1584 children and adolescents with ASD respectively reported prevalence rates of 56% (Kanne & Mazurek, 2011) and 53.7% (Mazurek, Kanne, & Wodka, 2013). Other studies have shown when controlling for sociodemographic variables (e.g., child age, gender, parent race, parent education, and ethnicity) that the prevalence rate drops to 25% (e.g., Hill et al., 2014). Although the prevalence rates vary within the literature, the potential severity of some aggressive behaviours are of concern as they may put the child, parent or another individual’s safety at risk.

There are a variety of risk factors identified in the literature for the presence of aggressive behaviour. Impairments related to the ASD phenotype have been shown to cause aggression, including poor communication and high frequency of repetitive or ritualistic behaviours, which is posited to compromise behavioural inhibition (Oliver, Petty, Ruddick & Bacarese-Hamilton, 2012). Resistance to change has also been identified as a risk factor for aggression (Kanne & Mazurek, 2011), along with self-injurious behaviours, sensory problems, and sleep disturbances (Mazurek et al., 2013). Interestingly a more severe degree of impairment in adaptive functioning has not been shown to significantly predict aggression, suggesting aggressive behaviours can present in children across the autism spectrum (McClintock, 2003; Oliver et al., 2012).

2.1.3. Self-injury

Self-injurious behaviours (SIBs) exist on a continuum, with the most severe including eye gouging and repetitive head banging (Durerden et al., 2012). These behaviours can result in permanent tissue damage in the form of lacerations, contusions, and abrasions (Taylor, Oliver, & Murphy, 2011). A meta-analysis of
studies conducted over the past 30 years identified that individuals with ASD were six times more likely to engage in SIBs than those without ASD (McClintock et al., 2003). The prevalence of SIBs in children with intellectual disabilities ranges from 4% to 12% in comparison to 33% to 50% in children with ASD (Baghdadli, Pascal, Grisi, & Aussilloux, 2003; Duerden et al., 2012; Richards et al., 2012). In some cases, severe SIBs may be managed in children with ASD with bilateral restraints, the use of tranquillising medications, and hospitalisation (Mandell, 2008; Watchel et al, 2009). Although severe, these measures are often taken to decrease the likelihood of serious physical harm occurring to the child or the child’s family or carers.

2.1.4 Suicidal ideation and attempts

Suicidal ideation or attempts have been identified in a substantial minority of children with ASD. In a sample of 791 children with ASD, 10.9% of children had suicidal ideation and 7.2% had made attempts (Mayes, Gorman, Hillwig-Garcia, & Syed, 2013). These findings represented a 28-fold elevation in suicidal behaviour in children with ASD compared to their typically developing peers.

2.2 Impact of challenging behaviours on parent mental health

Constellations of these challenging behaviours occur across the autism spectrum and can be of an ongoing nature, with parents encountering such events on a regular (sometimes daily) basis. In response, parents develop a hypervigilant style of parenting with heightened watchfulness and preparation for action to protect their child, family, and self (Larson, 2010; Woodgate, Ateah, & Secco, 2008); “You are walking on eggshells 24 hours a day…We were just drowning in autism” (Woodgate, 2008, p. 1079). Parents living in these stressful environments exhibit clinically
significant problems in daily social and occupational functioning (Larson 2010; Oberleitner, Ball, Gillette, Naseef, & Stamm, 2006).

It is important to acknowledge that not all parents of children with ASD report experiencing mental health difficulties or significantly challenging behaviours as part of their parenting experience. Children with ASD are highly heterogeneous in presentation, thus not all children with ASD will exhibit severely challenging behaviours. There is increasing evidence that parents can experience positive gains as a result of raising a child with ASD, including personal growth, improved relationships with others, increased patience, empathy, spiritual growth, and greater family connection (Bayat, 2007; Hastings & Taunt, 2002; Pakenham, Samios, & Sofronoff, 2005). As research in this area grows we will likely develop a greater understanding of the protective and distinguishing factors that elucidate why some parents do not report any significant mental health difficulties as a result of the parenting experience.

When reviewing the literature regarding the mental health in parents of children with ASD there is an obvious dearth of research exploring fathers’ reactions. This is even more evident in literature examining the impact of parenting a child with ASD who exhibits challenging behaviours. It is important to keep this in mind when considering implications of findings, as it cannot be assumed that research conducted largely with mother can be generalised to fathers. This has critical implications for understanding and providing effective support to parents of both genders. Despite the low representation of fathers in ASD parenting research, it is still apparent that both fathers and mothers of children with ASD report more mental health difficulties than parents of children in other clinical and non-clinical groups (Benjak 2009; Bitsika & Sharpley, 2004; Kuuikkso-Gauffun et al., 2013; Singer, 2006).
Research consistently demonstrates that there are higher incidence rates of depression and anxiety amongst parents of children with ASD compared to parents of typically developing children (e.g., Bitsika & Sharpley, 2004; Brobst, Clopton, & Hendrick, 2009; Silva & Schalock, 2012; Zablotsky, Bradshaw, & Stuart, 2013), children with Down syndrome (Dabrowska & Pisula, 2010), and other disabilities (Reed & Osborne, 2013). Depression and anxiety are often considered primary indicators of stress, despite the challenge of establishing a relationship between stress and distress (Wolf, Noh, Fisman, & Speechley, 1989). For example, there may be more factors than measured which contribute to parent distress that are not directly linked to raising a child with ASD (e.g., pre-existing pathology or other environmental stressors).

Parenting stress, defined as the experience of distress or discomfort that results from demands associated with the role of parenting (Deater-Deckard, 1998), is widely researched in the ASD literature. Parenting stress is reported as high in parents of children with ASD when compared to parents of typically developing children (Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009; Lee et al., 2009; Rao & Beidel, 2009), children with other disabilities (e.g., Blacher & McIntyre, 2006; Bouma & Schweitzer, 1990; Watson, Coons, & Hayes., 2012), and children with externalising behaviours (e.g., Abbeduto et al., 2004; Blacher & McIntyre, 2006; Estes et al., 2009). This stress can impact their ability to parent, their ability to manage their child’s special needs, and to maintain a marital relationship (Ludlow, Skelly, & Rohleder, 2011; Myers, Mackintosh, & Goin-Kochel, 2009).

Stress has been attributed to the child’s challenging behaviours (e.g., Bromley, Hare, Davison, & Emerson, 2004; David & Carter, 2008; Lecavalier, Leone, & Wiltz, 2006), however, the characteristics of challenging behaviours and
the impact of these behaviours on parental stress are inconsistent. For example, some findings indicate ASD symptom severity and resulting behaviours do not have a positive association with parenting stress (e.g., Hastings et al., 2005; Manning, Wainwright, & Bennett, 2011). These findings are unexpected, as greater symptom severity appears likely to result in higher levels of dependency on parents and increasing strain in meeting the demands associated with the role of parenting. Furthermore, it would not be unusual for the behaviours previously discussed (i.e., elopement, self-injurious behaviour, and aggression) to result in increased parent stress given the level of risk to the child, parent, and others that may be involved.

Inconsistent findings in the literature investigating the association between challenging behaviours and parent stress may, in part, be the result of methodological variation including how stress is defined as a construct and subsequently assessed (McStay, Dissanayake, Scheeren, Koot, & Begeer, 2014). For example, some researchers have referred to parents’ experience of stress as parenting stress (i.e. distress or discomfort resulting from demands associated with the role of parenting) (Deater-Deckard, 1998) (e.g., McStay et al., 2014), while others have employed more general constructs of stress (e.g., Abbeduto et al., 2004) or psychological distress (e.g., Bromley et al., 2004). The lack of a clear and consistent definition is problematic when seeking to interpret findings at an aggregate level to inform a greater understanding of the type of stress that parent’s experience.

A more recent definition of stress that has been introduced to the ASD literature is posttraumatic stress symptoms (PTSS) (Casey et al., 2012). PTSS refers to posttraumatic stress disorder (PTSD) symptomatology arising from an event that does not meet one of the precipitating traumatic stressors specified in Criterion A of the diagnostic criteria for PTSD in the DSM (APA, 2013). The Casey et. al. paper is
the only study that has been published which explores the psychological presentation of PTSS in parents of children with ASD. Other studies supportive of this conceptualisation of stress in parents of children with ASD have used cortisol profiles as a biological indicator of PTSS. Results have demonstrated that some parents exhibit cortisol profiles that are comparable to clinical populations of individuals with PTSD (e.g., Foody, James, & Leader, 2014; Seltzer et al., 2010). These early findings beg the question; how many parents of children with ASD experience traumatic stress as a result of child behaviours that may threaten the safety of their child, themselves, or others? Furthermore, for parents go on to develop PTSD symptomatology in response to this event, how do mental health professionals conceptualise their mental health presentation?
3.1 Overview

The term Posttraumatic stress disorder (PTSD) was formalised in the 3rd edition of the DSM (APA, 1980). This formal recognition of the category of PTSD was a critical step in a detailed analysis of the effects of overwhelming experiences. They posited that it opened the door to a “systematic investigation of how people come to be overwhelmed, how different people organise tragic experiences over time, and how their suffering can be alleviated (van der Kolk & McFarlane, 1996 p. 4). The APA’s inclusion of PTSD as a diagnosis was closely related to the recognition of the effects of trauma on the veterans of the Vietnam War.

A diagnosis of PTSD is considered when an individual is exposed to a precipitating event specified in the DSM known as a *traumatic stressor* and, in response, develops other symptomatology consistent with PTSD diagnostic criteria (APA, 2013). The clinical profile of PTSD psychopathology varies; in some individuals fear-based re-experiencing, emotional and behavioural symptoms predominate, and in others, anhedonic or dysphoric mood states and negative cognitions, or arousal and reactive-externalising are more pronounced (APA, 2013). An individual may also exhibit a combination of these symptoms.

Individuals who meet PTSD criteria will not necessarily express concern about a traumatic event when presenting to a health professional. Instead they may present with a range of problems including mood disorders, anger, relationship difficulties, poor sleep, or physical health complaints such as headaches and gastrointestinal problems (Phoenix Australia-Centre for Posttraumatic Mental Health, 2015). The reasons behind not mentioning a traumatic event is considered, in
part, to be reflective of avoidance which is a diagnostic characteristic of PTSD (Australian Centre for Posttraumatic Mental Health, 2013).

3.2 Diagnosis

Diagnostic and Statistical Manual of Mental Disorders

Prior to the introduction of PTSD in the 3rd edition of the DSM, trauma-induced psychopathological abnormalities were defined in the 1st edition of the DSM (DSM-I; APA, 1952) as a “gross stress reaction” following exposure to “situations in which the individual has been exposed to severe physical demands or extreme emotional stress, such as in combat or in civilian catastrophe (fire, earthquake, explosion etc.)” (APA, 1980, p. 40). That is, psychological distress resulting from exposure to traumatic stress was dependent upon the individual’s adaptive capacity (Jones & Wessley, 2007). Strangely, in the midst of the Vietnam War, when the 2nd edition of the DSM (DSM-II; APA, 1968) was published, the diagnosis of ‘gross stress reaction’ was absent. It has been argued that political motivations were involved in the sudden disappearance of this diagnostic category (Bloom, 2000).

More than ten years later, the 3rd edition of the DSM (DSM-III; APA, 1980) included PTSD as a diagnostic entity within the anxiety disorder category. There was a distinct shift away from the adaptive capacity of the individual to the experience of a “psychologically traumatic event that is generally outside the range of usual human experience” (APA, 1980, p. 236). Exposure to a qualifying precipitant (traumatic stressor) as part of ‘Criterion A’ was required prior to the evaluation of whether other symptomatology, duration, and functional impairment criteria met PTSD diagnostic criteria (Kilpatrick, Resnick, & Acierno, 2009). Traumatic stressors included: “rape, assault, military combat, natural disasters, accidental man-made
disasters (car accidents with serious physical injury, airplane crashes, and large fires), and deliberate man-made disasters (bombing, torture, death camps)” (APA, 1980, p.236) (see Table 5). If an individual exhibited trauma-related symptomatology but had not been exposed to one of these defined traumatic stressors, their presentation was no longer considered within a trauma-related framework for possible PTSD diagnosis.
Table 5

Diagnostic criteria for Posttraumatic Stress Disorder (DSM-III, 1980)
(308.3/309.81)

A. Existence of a recognizable stressor that would evoke significant symptoms of distress in almost everyone.

B. Re-experiencing of the trauma as evidenced by at least one of the following:
   1. Recurrent and intrusive recollections of the event.
   2. Recurrent dreams of the event.
   3. Sudden acting or feeling as if the traumatic event were reoccurring, because of an association with an environmental or ideational stimulus.

C. Numbing of responsiveness to or reduced involvement with the external world, beginning sometime after the trauma, as shown by at least one of the following:
   1. Markedly diminished interest in one or more significant activities.
   2. Feeling of detachment or estrangement from others.
   3. Constricted affect.

D. At least two of the following symptoms that were not present before the trauma:
   1. Hyperalertness or exaggerated startle response.
   2. Sleep disturbance.
   3. Guilt about surviving when others have not, or about behavior required for survival.
   4. Memory impairment or trouble concentrating.
   5. Avoidance of activities that arouse recollection of the traumatic event.
   6. Intensification of symptoms by exposure to events that symbolise or resemble the traumatic event.

Specify if:

Posttraumatic Stress Disorder, Acute:
   A. Onset of symptoms within six months of the trauma.
   B. Duration of symptoms less than six months.

Posttraumatic Stress Disorder, Chronic or Delayed
Either of the following, or both:
   1) Duration of symptoms six months or more (chronic)
   2) Onset of symptoms at least six months after the trauma (delayed)
In the DSM-III-R (APA, 1987), Criterion A for PTSD became significantly more detailed and included secondary trauma (see Table 6). The traumatic stressors remained, thereby maintaining the notion that a non-specified DSM stressful event could not lead to PTSD but only transitory mental disturbance. Individuals who developed long-lasting psychopathology in response to extreme stress continued to be overlooked for consideration of a trauma-related disorder (Brewin, Lanius, Novas, Schnyder, & Galea, 2009).

In the DSM-IV (APA, 1994) changes to the PTSD diagnostic criteria occurred, along with the introduction of a new trauma-related disorder, Acute Stress Disorder (note: these changes remained static in the DSM-IV-TR; APA, 2000). A division arose within the DSM-IV PTSD working group regarding Criterion A, with some members questioning the utility of specifying an etiological precipitant. It was argued that the event itself was not important, but instead how the event was subjectively perceived. If it was perceived as traumatic, then that would determine whether a person became symptomatic (Rosen, 2004). It was further argued that clinicians did not require Criterion A and could diagnose based on presenting symptoms, duration, and impairment (Rosen, 2004). Members in opposition countered with concerns over “criterion creep” (more causal events to satisfy Criterion A) and concerns regarding how to specify the psychobiological mechanisms underlying symptomatology arising from extremely diverse events (Rosen, 2004). Criterion A was ultimately retained and included a subjective component (see Table 7). The list of traumatic stressors was expanded to include violent personal assault (sexual assault, physical attack, robbery, mugging), being kidnapped, being taken hostage, and being diagnosed with a life-threatening illness (APA, 1994).
Acute Stress Disorder was also introduced into the DSM-IV (APA, 1994) and subsequent editions to account for the temporal gap between the exposure to a traumatic stressor and development of PTSD one month later (Friedman, Keane, & Resick, 2014). A diagnosis of Acute Stress Disorder was given when the psychological disturbance lasted for a minimum of two days and a maximum of four weeks (APA, 1994).
Table 6

Diagnostic criteria for Posttraumatic Stress Disorder (DSM-III-R, 1987) (309.89)

A. The person has experienced an event that is outside the range of usual human experience and that would be markedly distressing to almost anyone, e.g., serious threat to one's life or physical integrity; serious threat or harm to one's children, spouse, or other close relatives and friends; sudden destruction of one's home or community; or seeing another person who has recently been, or is being, seriously injured or killed as the result of an accident or physical violence.

B. The traumatic event is persistently reexperienced in at least one of the following ways:

1. Recurrent and intrusive distressing recollections of the event.
2. Recurrent distressing dreams of the event.
3. Sudden acting or feeling as if the traumatic event were recurring (includes a sense of reliving the experience, illusions, hallucinations, and dissociative [flashback] episodes, even those that occur upon awakening or when intoxicated).
4. Intense psychological distress at exposure to events that symbolize or resemble an aspect of the traumatic event, including anniversaries of the trauma.

C. Persistent avoidance of stimuli associated with the trauma or numbing of general responsiveness (not present before the trauma), as indicated by at least three of the following:

1. Efforts to avoid thoughts or feelings associated with the trauma.
2. Efforts to avoid activities or situations that arouse recollections of the trauma.
3. Inability to recall an important aspect of the trauma (psychogenic amnesia).
4. Markedly diminished interest in significant activities.
5. Feeling of detachment or estrangement from others.
6. Restricted range of affect, e.g., unable to have loving feelings.
7. Sense of a foreshortened future, e.g., does not expect to have a career, marriage, or children, or a long life.

D. Persistent symptoms of increased arousal (not present before the trauma), as indicated by at least two of the following:

1. Difficulty falling or staying asleep.
2. Irritability or outbursts of anger.
3. Difficulty concentrating.
4. Hypervigilance.
5. Exaggerated startle response.
6. Physiologic reactivity upon exposure to events that symbolize or resemble an aspect of the traumatic event (e.g., a woman who was raped in an elevator breaks out in a sweat when entering any elevator).

E. Duration of the disturbance (symptoms in B, C, and D) of at least one month.

Specify delayed onset if the onset of symptoms was at least six months after the trauma.
Table 7  
**Diagnostic criteria for Posttraumatic Stress Disorder (DSM-IV, 2000) (309.81)**

A. The person has been exposed to a traumatic event in which both of the following were present:

1. The person experienced, witnessed, or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others.
2. The person’s response involved intense fear, helplessness, or horror.

B. The traumatic event is persistently reexperienced in one (or more) of the following ways:

1. Recurrent and intrusive distressing recollections of the event, including images, thoughts, or perceptions.
2. Recurrent distressing dreams of the event.
3. Acting or feeling as if the traumatic event were recurring (includes a sense of reliving the experience, illusions, hallucinations, and dissociative flashback episodes, including those that occur on awakening or when intoxicated).
4. Intense psychological distress at exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event.
5. Physiological reactivity on exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event.

C. Persistent avoidance of stimuli associated with the trauma and numbing of general responsiveness (not present before the trauma), as indicated by three (or more) of the following:

1. Efforts to avoid thoughts, feelings, or conversations associated with the trauma.
2. Efforts to avoid activities, places, or people that arouse recollections of the trauma.
3. Inability to recall an important aspect of the trauma.
4. Markedly diminished interest or participation in significant activities.
5. Feeling of detachment or estrangement from others.
6. Restricted range of affect (e.g., unable to have loving feelings).
7. Sense of a foreshortened future (e.g., does not expect to have a career, marriage, children, or a normal life span).

D. Persistent symptoms of increased arousal (not present before the trauma), as indicated by two (or more) of the following:

1. Difficulty falling or staying asleep.
2. Irritability or outbursts of anger.
3. Difficulty concentrating.
4. Hypervigilance.
5. Exaggerated startle response.

E. Duration of the disturbance (symptoms in Criteria B, C, and D) is more than 1 month.

F. The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.
In the DSM-5 (APA, 2013) PTSD (and Acute Stress Disorder) was relocated from the anxiety category of disorders to a new category, ‘trauma and stressor-related disorders’. The addition of this new category seems appropriate given PTSD is not exclusively an anxiety-based disorder (Byllesby, Durham, Forbes, Armour, & Elhai, 2016). The PTSD diagnostic criteria expanded to capture a more comprehensive profile of a posttraumatic stress response (see Table 8). Changes included the addition of a new cluster of symptoms (negative altercations in cognition and mood), Criterion A2 (i.e., immediate response of intense fear, helplessness, or horror after exposure to a traumatic stressor) removed, and avoidance symptoms (Criterion C) updated to differentiate active avoidance from passive avoidance (Criterion C) (O’Donnell et al., 2014).

The list of traumatic stressors remained predominately static, with the exception of ‘sexual assault’ being replaced with ‘sexual violence’ (e.g., forced sexual penetration, alcohol/drug-facilitated sexual penetration, abusive sexual contact, noncontact sexual abuse, sexual trafficking) and the recognition of repeated or extreme exposure to aversive details of traumatic events (e.g., first responders collecting human remains) (APA, 2013). The changes to the diagnostic criteria and traumatic stressors continue to highlight the extensive heterogeneity in the clinical expression of PTSD (Friedman & Resick, 2014).
Table 8  
*Diagnostic criteria for Posttraumatic Stress Disorder (DSM-5, 2013) (309.81)*

The following criteria apply to adults.

**A.** Exposure to actual or threatened death, serious injury, or sexual violence in one (or more) of the following ways:

1. Directly experiencing the traumatic event(s).
2. Witnessing, in person, the event(s) as it occurred to others.
3. Learning that the traumatic event(s) occurred to a close family member or close friend. In cases of actual or threatened death of a family member or friend, the event(s) must have been violent or accidental.
4. Experiencing repeated or extreme exposure to aversive details of the traumatic event(s) (e.g., first responders collecting human remains; police officers repeatedly exposed to details of child abuse).
   - **Note:** Criterion A4 does not apply to exposure through electronic media, television, movies, or pictures, unless this exposure is work related.

**B.** Presence of one (or more) of the following intrusion symptoms associated with the traumatic event(s), beginning after the traumatic event(s) occurred:

1. Recurrent, involuntary, and intrusive distressing memories of the traumatic event(s).
2. Recurrent distressing dreams in which the content and/or affect of the dream are related to the traumatic event(s).
3. Dissociative reactions (e.g., flashbacks) in which the individual feels or acts as if the traumatic event(s) were recurring. (Such reactions may occur on a continuum, with the most extreme expression being a complete loss of awareness of present surroundings.)
4. Intense or prolonged psychological distress at exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event(s).
5. Marked physiological reactions to internal or external cues that symbolize or resemble an aspect of the traumatic event(s).

**C.** Persistent avoidance of stimuli associated with the traumatic event(s), beginning after the traumatic event(s) occurred, as evidenced by one or both of the following:

1. Avoidance of or efforts to avoid distressing memories, thoughts, or feelings about or closely associated with the traumatic event(s).
2. Avoidance of or efforts to avoid external reminders (people, places, conversations, activities, objects, situations) that arouse distressing memories, thoughts, or feelings about or closely associated with the traumatic event(s).

**D.** Negative alterations in cognitions and mood associated with the traumatic event(s), beginning or worsening after the traumatic event(s) occurred, as evidenced by two (or more) of the following:

1. Inability to remember an important aspect of the traumatic event(s) (typically due to dissociative amnesia and not to other factors such as head injury, alcohol, or drugs).
2. Persistent and exaggerated negative beliefs or expectations about oneself, others, or the world (e.g., “I am bad,” “No one can be trusted,” “The world is completely dangerous,” “My whole nervous system is permanently ruined”).

3. Persistent, distorted cognitions about the cause or consequences of the traumatic event(s) that lead the individual to blame himself/herself or others.

4. Persistent negative emotional state (e.g., fear, horror, anger, guilt, or shame).

5. Markedly diminished interest or participation in significant activities.

6. Feelings of detachment or estrangement from others.

7. Persistent inability to experience positive emotions (e.g., inability to experience happiness, satisfaction, or loving feelings).

E. Marked alterations in arousal and reactivity associated with the traumatic event(s), beginning or worsening after the traumatic event(s) occurred, as evidenced by two (or more) of the following:

1. Irritable behavior and angry outbursts (with little or no provocation) typically expressed as verbal or physical aggression toward people or objects.

2. Reckless or self-destructive behavior.

3. Hypervigilance.

4. Exaggerated startle response.

5. Problems with concentration.

6. Sleep disturbance (e.g., difficulty falling or staying asleep or restless sleep).

F. Duration of the disturbance (Criteria B, C, D, and E) is more than 1 month.

G. The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.

H. The disturbance is not attributable to the physiological effects of a substance (e.g., medication, alcohol) or another medical condition.

Specify whether:

- **With dissociative symptoms:** The individual’s symptoms meet the criteria for posttraumatic stress disorder, and in addition, in response to the stressor, the individual experiences persistent or recurrent symptoms of either of the following:

  1. **Depersonalization:** Persistent or recurrent experiences of feeling detached from, and as if one were an outside observer of, one’s mental processes or body (e.g., feeling as though one were in a dream; feeling a sense of unreality of self or body or of time moving slowly).

  2. **Derealization:** Persistent or recurrent experiences of unreality of surroundings (e.g., the world around the individual is experienced as unreal, dreamlike, distant, or distorted).

    ○ **Note:** To use this subtype, the dissociative symptoms must not be attributable to the physiological effects of a substance (e.g., blackouts, behavior during alcohol intoxication) or another medical condition (e.g., complex partial seizures).

Specify if:

- **With delayed expression:** If the full diagnostic criteria are not met until at least 6 months after the event (although the onset and expression of some symptoms may be immediate).
3.3 Prevalence of PTSD

The 12-month and lifetime prevalence rates for PTSD in Australia have been estimated as 4.4% and 7.2% respectively (McEvoy, Grove, & Slade, 2011). There is no reported prevalence rate for PTSD in parents of children with ASD. This is surprising, as a subpopulation of parents are likely to have experienced events defined as traumatic stressors as a result of parenting challenging behaviours (e.g., self-injurious behaviours, danger to safety resulting from elopement). There may be several reasons for the lack of reported prevalence of PTSD in parents of children with ASD. For example, parents of children with ASD are considered low seekers of professional help for themselves. Parents tend to adopt an exclusive focus on their child’s management and well-being and report devising their own coping strategies to alleviate their psychological distress (e.g., Neely-Barnes, Hall, Roberts, & Graff, 2011; Safe, Joosten, & Molineux, 2012, Woodgate et al., 2008). Another hypothesis is that parents may be more commonly diagnosed with mood or/and anxiety disorders, which in the presence of a traumatic stressor, form two underlying factors of PTSD, as opposed to discrete diagnoses (Byllesby et al., 2016).

3.4 Aetiology of PTSD

Although lifetime prevalence of exposure to Criterion A traumatic stressors is thought to be between 40-90% in the worldwide general population, the overall lifetime prevalence of PTSD is estimated at 7-12% (Breslau, 2001; Kessler, Sonnega, Bromet, Hughes, & Nelson, 1995). This means that exposure to a traumatic stressor does not entirely explain the aetiology of the disorder, and that a complex interrelationship among many different factors including biological, environmental,
and life experience likely contributes to the development of PTSD (Ford, Grasso, Elhai, & Courtois, 2015).

Evidence of a genetic vulnerability as a causal factor in the development of PTSD comes from transgenerational research (e.g., Koenen et al., 2003; Yehuda, Schmeidler, Giller, Siever, & Binder-Brynes, 1998) and epidemiologic studies with twins (e.g., Stein, Jang, Taylor, Vermon, & Livesley, 2002). Such studies suggest a potential inborn genetic difference that predisposes individuals to the development of PTSD, although the influence of related factors including shared family environment cannot be definitively ruled out. The identification of a single gene is considered unlikely given PTSD is a ‘phenotypically complex’ phenomenon that involves alterations in behaviours, cognition, emotion, and physiology (Ford et al., 2015). Neurobiology has also been implicated in the development of PTSD, in particular a smaller hippocampal volume and abnormalities in the septum pellucidum (Gross & Hen, 2004; May, Chen, Gilbertson, Shenton, & Pitman, 2004; Talbot, 2004).

Other distal and static predictors posited to play a role in the development of PTSD symptoms include family history of psychopathology (e.g., generalised anxiety disorder), prior trauma (interpersonal violence), and the exposed person’s own psychological difficulties (Ozer, Best, Lipsey, & Weiss, 2003). Individuals with pre-existing psychiatric conditions, including severe mood and anxiety disorders, have been identified as more likely to report a history of exposure to psychological trauma and both past and current PTSD (Mueser, Essock, Haines, Wolfe, & Xie, 2004; Mueser et al., 2001). It is currently unclear whether PTSD precedes and exacerbates other psychiatric disorders, or whether symptoms of psychiatric disorders may make individuals vulnerable to the development of PTSD (Ford et al.,

**Gender**

In the general population, PTSD is more prevalent among females than among males across the lifespan (APA, 2013). Females also tend to experience PTSD for a longer duration than males, which is considered, in part, due to a greater likelihood of exposure to traumatic events such as rape, and other forms in interpersonal violence (Kessler et al., 2005). Research has yet to reliably identify any other biopsychosocial factors that may assist in explaining the gender difference (ACPMH, 2013). Further, gender differences become attenuated or non-significant in populations that are exposed specifically to Criterion A stressors (APA, 2013).

### 3.5 Differential diagnosis and co-morbidity

Other common diagnoses that may arise from exposure to a traumatic stressors include depression, anxiety disorders (e.g., panic disorder, generalised anxiety disorder, specific phobias), substance abuse/dependence and adjustment disorders (ACPMH, 2013). Data from the 2007 Australian National Mental Health and Wellbeing study (2007) found that 86% and 77% of men and women with PTSD also met criteria for another clinical diagnosis. This included anxiety (52% men, 54% women), depression (50% men, 51% women), and substance use disorders (65% men, 32% women). Although not diagnostic in nature, other common characteristics associated with PTSD that can influence treatment effectiveness or become targets for intervention include guilt, aggression, somatic complaints, relationship difficulties, and impaired occupational functioning (ACPMH, 2013).
Co-morbid diagnoses of mood and/or anxiety are high, as the underlying factors of PTSD involve anxious-related factors (i.e., re-experiencing, avoidance, and anxious arousal), a depression-related factor (i.e., numbing), and dysphoric arousal which has a strong relationship with both anxiety and depression (Byllesby et al., 2016). Although the heterogeneity of PTSD’s association with anxiety and depressive constructs requires additional empirical exploration, PTSD is posited to be distinguished by the situation-specific nature of its symptom-complex (i.e., by linking current symptomatology with a past traumatic stressor) (Keane, Taylor, & Penk, 1997). Symptoms of avoidance are associated with present reminders of these traumatic stressors and physiological reactivity associated with memories of traumatic stressors (Keane et al., 1997).

3.6 The PTSD Criterion A controversy

The idea that a clinical disorder could be explained entirely by an environmental event rather than the characteristics of the person, or their interaction, is unique to the history of diagnostic criteria in the DSM. It is therefore no surprise that the PTSD Criterion A that lists specific aetiological events that may be considered ‘traumatic’ became immediately controversial. An ongoing debate continues regarding the utility of specifying the types of events that are considered inherently traumatic and, therefore, definitively aetiological. The assumption that exposure to a specific traumatic stressor is the unique cause of a set of stress response symptomatology is problematic for two reasons. The first is that epidemiological studies have reported traumatic stressors to be more prevalent than originally assumed, and that only a small portion (estimated to be less than 10%; Breslau, 2009) of individuals exposed to a traumatic stressor develop symptoms
consistent with the other criteria for a PTSD diagnosis (Yehuda & McFarlane, 1995). The second is that stressors vary along a number of dimensions including magnitude, complexity, frequency, duration, predictability, and controllability (Weathers & Keane, 2007). Although at the extremes of the traumatic stressor spectrum (e.g., life-threatening catastrophe versus minor inconvenience) the events are discrete and qualitatively distinct, there is a wide range of potential traumatic events with no crisp boundaries demarcating ordinary stressors from traumatic stressors (Weathers & Keane, 2007).

Some clinicians have argued that a diagnosis of PTSD does not require a predefined traumatic stressor, and that PTSD can be reliably established by the presence of trauma-related symptomatology (Criteria B-H) (Maier, 2007). Nevertheless, Criterion A remains, and PTSD (and Acute Stress Disorder) remain the only diagnoses in the current edition of the DSM that require a predefined environmental precipitant.

3.7 The physiological profile of PTSD in parents of children with ASD

As noted in the previous chapter, recent research findings have expanded our understanding of the type of stress that some parents of children with ASD experience. Through the collection of saliva samples from parents of children with ASD, researchers have been able to examine cortisol, the main hormone product of the hypothalamic-pituitary-adrenocortical (HPA) axis, which is activated during a stress response. This physiological process is considered to be a primary biological marker of stress reactivity (Adam & Gunner, 2001; Foody et al., 2014). Elevations in cortisol have been observed in response to acute experiences of stress, while reduced or blunted levels of cortisol have been observed in response to chronic stress (HPA
hypoactivity). Although HPA hypoactivity may seem counterintuitive, this cortisol profile is empirically validated having been observed in combat soldiers, Holocaust survivors and, indeed, individuals diagnosed with posttraumatic stress disorder (PTSD) (Heim, Ehlert, & Hellhammer, 2000; Miller, Chen, & Zhou, 2002; Yehuda, Boisoneau, Lowy, & Giller, 1995). More recently, HPA hypoactivity has been documented in some parents of children with ASD (e.g., Foody et al., 2014, Seltzer et al., 2010).

When compared to control groups, Seltzer et al. (2010) reported low levels of cortisol in mothers of adolescents and adults with ASD and Foody et al. (2014) found low cortisol levels in mother–father dyads of younger children with ASD. Challenging child behaviours predicted reduced maternal cortisol levels. These behaviours included self-injurious behaviour, repetitive behaviour, uncooperative behaviour and socially offensive behaviour (Seltzer et al., 2010). Mothers’ cortisol levels remained low even after controlling for maternal age, prescription medication use, and saliva collection time (Seltzer, 2010). Evidence of HPA hypoactivity is alarming, as it indicates that a subpopulation of parents of children with ASD exhibit cortisol profiles comparable to clinical populations of individuals with PTSD. This subpopulation of parents who exhibit HPA hypoactivity are at risk of compromised mental and physical health, including decreased immunity, fatigue-like symptoms, and increased vulnerability to stress-related diseases including hypertension, stroke, and coronary heart disease (Sapolsky, 2004). Additionally, their efficacy as caregivers may be compromised (Cabizuca, Marques-Portella, Mendlowicz, Coutinho, & Figueira, 2009).

Interestingly, Foody et al. (2014) found mothers in their sample reported clinical levels of parental distress (Parenting Stress Index-Short Form) but that their
group depression scores fell within the normal range and group anxiety within the mild range (Hospital Anxiety and Depression Scale). Additionally, fathers reported parental distress within the normal range, and group anxiety and depression fell within the normal range. Despite normal to low levels of self-reported depression and anxiety, at a physiological level, these parents exhibited HPA hypoactivity. These results highlight the importance of future research in expanding our knowledge of ways to screen for chronic stress reactions in parents.

Foody et al (2014) also investigated ambulatory blood pressure and heart rate variability in parents of children with ASD, as these represent two additional indicators of chronic stress. Their results indicated that fathers exhibited significantly higher blood pressure and heart rate variability than mothers. Fathers may therefore be at an increased risk of cardiovascular disease due to higher blood pressure and mothers may also be at increased risk of cardiovascular disease as a result of reduced heart rate variability. Stress management training has been posited as effective in reducing blood pressure variability (Garcia-Vera et al., 2004), and should therefore be considered as a modality for parent support.

A recent meta-analysis investigating parenting stress reported that there were very few programs dedicated to alleviating parenting stress (Bonis, 2016). Acceptance and commitment programs (Blackledge & Hayes, 2006) and multicomponent interventions addressing parent wellbeing and behavioural parent training (Singer, Ethridge, & Eldana, 2007) were reported to reduce reports of parent stress at least in the short-term, with a medium effect size.

The Australian Guidelines for the Treatment of Adults with Acute Stress Disorder and PTSD recommend trauma-focused cognitive behaviour therapy (TFCBT) as the most effective intervention (ACPMH, 2013). The ACPMH (2013)
guidelines suggest that if symptoms do not respond to TFCBT or other trauma-focussed intervention (e.g., eye movement desensitisation and reprocessing), evidence-based non-trauma-focussed psychological interventions (e.g., stress inoculation training) should be considered.

Further research is required to better understand whether there is a subpopulation of parents who experience PTSS or PTSD. This knowledge is important as, without reference to a trauma framework, this subpopulation is unlikely to be receiving optimal diagnostic outcomes and treatment recommendations, which likely has a negative impact on, not just the parent, but the child with ASD and the wider family.
Chapter 4: A review of parent mental health and its relationship with a traumatic stress framework

A review of the literature revealed a dearth of research investigating the validity of adopting a traumatic stress framework to conceptualise the psychological experience of a subpopulation of parents of children with ASD. The most frequently investigated mental health concerns included depression, anxiety, and stress. For some parents, a diagnosis of depression and/or anxiety may adequately encapsulate their presenting symptoms, however, for a subpopulation of parents who may be exposed to traumatic stressors, depressive and anxiety symptomatology may be more effectively accounted for by a traumatic stress framework.

The following paper (Stewart, McGillivray, Forbes, & Austin, 2016) investigated the impact of raising a child with ASD and sought to identify the behavioural clusters that were predictive of traumatic stress. Two conceptualisations of trauma were explored; traumatic stress as specifically defined in the DSM-5 and the presence of PTSS in the absence of a traumatic stressor (i.e., Criterion A, PTSD).
Paper 1


Preprint of the original paper.
# Authorship Statement

## 1. Details of publication and executive author

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<th>Publication details</th>
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<tr>
<td>Parenting a child with an autism spectrum disorder: a review of parental mental health and its relationship to a trauma-based conceptualisation</td>
<td>Advances in Mental Health</td>
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<th>School/Institute/Division if based at Deakin; Organisation and address if non-Deakin</th>
<th>Email or phone</th>
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<td><a href="mailto:david.austin@deakin.edu.au">david.austin@deakin.edu.au</a></td>
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## 2. Inclusion of publication in a thesis

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If Yes, please complete Section 3
If No, go straight to Section 4.

## 3. HDR thesis author’s declaration

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<tr>
<td>Michelle Stewart</td>
<td>School of Psychology</td>
<td>Traumatic stress in parents of children with autism spectrum disorder</td>
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If there are multiple authors, give a full description of HDR thesis author’s contribution to the publication (for example, how much did you contribute to the conception of the project, the design of methodology or experimental protocol, data collection, analysis, drafting the manuscript, revising it critically for important intellectual content, etc.)

I declare that the above is an accurate description of my contribution to this paper, and the contributions of other authors are as described below.

Signature and date: 30th July 2016

## 4. Description of all author contributions

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<th>Name and affiliation of author</th>
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<td>Michelle Stewart</td>
<td>Conceptual development of paper, drafting of manuscript, revisions, principal author.</td>
</tr>
<tr>
<td>A/Prof David Austin</td>
<td>Conceptual development of paper, review and feedback for manuscript.</td>
</tr>
<tr>
<td>Prof Jone McGillivray</td>
<td>Review and feedback for manuscript.</td>
</tr>
<tr>
<td>Prof David Forbes</td>
<td>Review and feedback for manuscript.</td>
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5. Author Declarations

I agree to be named as one of the authors of this work, and confirm:

i. that I have met the authorship criteria set out in the Deakin University Research Conduct Policy,
ii. that there are no other authors according to these criteria,
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<td>A/Prof David Austin</td>
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<td>Prof Jane McGillivray</td>
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<td>3rd August 2016</td>
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<td>Prof David Forbes</td>
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<td>4th August 2016</td>
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6. Other contributor declarations

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* If an author or contributor is unavailable or otherwise unable to sign the statement of authorship, the Head of Academic Unit may sign on their behalf, noting the reason for their unavailability, provided there is no evidence to suggest that the person would object to being named as author.

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Parenting a child with an autism spectrum disorder: a review of parent mental health and its relationship to a trauma-based conceptualisation

Michelle Stewart, Jane A. McGillivray, David Forbes and David W. Austin

School of Psychology, Deakin University, Melbourne, VIC, Australia; Phoenix Australia—Centre for Posttraumatic Mental Health, Department of Psychiatry, The University of Melbourne, Australia

The impact on parental psychological functioning as a result of living with disruptive, challenging, and dangerous behaviours exhibited by some children with Autism Spectrum Disorder (ASD) is investigated. Core features of ASD along with aggression, elopement, self-injury, and suicidal ideation can cause significant parental distress. This parenting experience may be associated with depression, anxiety, somatisation, and anger-hostility. It is proposed that a traumatic stress framework may assist in conceptualising some parents’ experiences and psychological symptomatology. A systematic review revealed only one study that had explored posttraumatic stress symptoms amongst parents of children with ASD. Consequently, a narrative literature review has been conducted to explore this emerging area of enquiry. The Diagnostic and Statistical Manual of Mental Health Disorders (fifth edition) recognises direct experience as well as witnessing actual or threatened serious injury as a traumatic event that can lead to trauma-related psychopathology. Despite some parents of children with ASD experiencing traumatic events (e.g. their child engaging in self-injurious behaviours), prevalence rates of Posttraumatic Stress Disorder amongst this population are unknown. Further research is required to determine the validity of adopting a traumatic stress framework when considering parent symptomatology, and if such a framework were valid, there would be significant implications for optimising support and intervention for parents.

Introduction

Autism Spectrum Disorder (ASD) is a lifelong, complex developmental disorder that has no clear aetiology, cure, or standard medical treatment (Oberleitner, Ball, Gillette, Naseef, & Stamm, 2006; Woodgate, Ateah, & Secco, 2008). ASD is characterised by impairments in reciprocal social communication and social interaction, and restricted, repetitive patterns of behaviour or interests (American Psychiatric Association, 2013). These symptoms are present in early childhood and impair everyday functioning, often leading to a diagnosis within the first few years of life. Recent prevalence rates indicate ASD affects approximately 1.47% of the population (Centers for Disease Control and Prevention,
PTSS in parents of children with ASD

The pervasive deficits and behaviours that some children with ASD exhibit have been associated with elevated parenting stress and psychopathology (Davis & Carter, 2008).

The aims of this paper are threefold: (1) to identify child behaviours that have a pervasive impact upon the mental health and well-being of parents who have children with ASD, (2) to review parent mental health outcomes, and (3) to consider the validity of applying a traumatic stress framework to encapsulate some parenting experiences.

Factors that influence parental mental health and well-being

Disruptive, challenging, and dangerous behaviours

Parents have reported the core deficits associated with ASD (impaired social communication and restricted and/or repetitive behaviours) as distressing and disruptive behaviours, which at times challenge their parenting capacity (Davis & Carter, 2008). Other common behaviours that are likely to influence parental mental health include aggression (Matson & Rivet, 2008; Richards, Oliver, Nelson, & Moss, 2012), property destruction and violence towards others, primarily in the form of kicking or biting (McClintock, Hall, & Oliver, 2003). Longitudinal studies demonstrate that these behaviours tend to be unremitting (Eisenhower, Baker, & Blacher, 2005) and may lead to hospitalisation, out of home care, or police involvement (Myers, Mackintosh, & Goin-Kochel, 2009).

Elopement is a behaviour that occurs when a child wanders or bolts from a specified area without parent permission (Lang et al., 2010). This behaviour demands vigilant parenting, with some parents reporting that they monitor their child 24 hours a day to ensure his or her safety (Myers et al., 2009). In a community sample of 1200 children with ASD, 49% were reported to have eloped at some point, with 26% missing long enough to cause serious concern. Of those missing, 24% were judged to be in danger of drowning and 65% in danger of incurring a traffic injury (Anderson et al., 2012). Most commonly, 74% of these children disappeared from their own home, or that of another. Elopement has been linked to the highest standardised mortality for children with ASD between the ages of 5 and 10 years (5.4%) (Shavelle, Strauss, & Pickett, 2001). In a study of 13,111 ambulatory individuals with ASD in California between 1983 and 1997, 3.9% of children with ASD with no or mild intellectual disability who had eloped drowned, a figure which rose to 13.7% for those with a moderate, severe, or profound intellectual disability (Shavelle et al., 2001).

A meta-analysis of research from the past 30 years identified that individuals with ASD were six times more likely to engage in self-injurious behaviours (SIBs) than those without ASD (McClintock et al., 2003). These behaviours are on a continuum and at their most severe include eye gouging and severe head banging (Duerden et al., 2012). The prevalence of SIBs in children with intellectual disabilities ranges from 4% to 12% in comparison to 33% to 50% in children with ASD (Duerden et al., 2012; Richards et al., 2012).

There is also increased recognition that individuals with ASD are at risk of suicidal ideation or attempts. One of the most significant contributors to increased risk, irrespective of ASD severity or comorbid intellectual impairment, is poor communication and deficits in expressing feelings (Richa, Fahed, Khoury, & Mishara, 2014). In a sample of 791 children with ASD, 10.9% of children had suicidal ideation and 7.2% had made attempts (Mayes, Gorman, Hillwig-Garcia, & Syed, 2013). These findings represented a
28-fold elevation in suicidal behaviour in children with ASD compared to typically developing children and signal an urgent need for more research into prevention strategies.

Constellations of these challenging, disruptive, and dangerous behaviours are of an ongoing nature (sometimes daily occurrences), and can present in children irrespective of ASD severity or comorbid intellectual impairment (Anderson et al., 2012; McClintock et al., 2003). In response, parents often develop a hypervigilant style of parenting with heightened watchfulness and preparation for action to protect their child, their family, as well as themselves (Woodgate et al., 2008). Clinically significant problems in daily social and occupational functioning have been reported for parents living in these highly charged environments (Oberleitner et al., 2006).

Social factors
It has been posited that negative public attitudes towards disabilities may lead parents to experience their child being socially devalued or disrespected. This experience can lead to significant emotional consequences which socially debilitate mothers (Green, Davis, Karshmer, Marsh, & Straight, 2005). Parents frequently report experiencing social isolation from family and friends (Neely-Barnes, Hall, Roberts, & Graff, 2011), which some parents perceive as a lack of acceptance and understanding of autistic behaviours (Gray, 2002). Mothers have also reported feeling that their parenting capacity was being scrutinised by the general public with comments like, “You shouldn’t even let her out in public. You should keep kids like that at home” (Neely-Barnes et al., 2011, p. 214).

Parental psychological functioning
Depression and anxiety
Parent depression and anxiety are frequently investigated clinical constructs that are linked to parent distress, and posited to be indicative of elevated levels of parenting stress (Davis & Carter, 2008; Ekas & Whitman, 2010). For example, mothers of children with ASD (n = 30) and behaviour disorders (n = 30) reported statistically higher levels of parenting stress and depression than parents of children with Down syndrome (n = 30) and typically developing children (n = 60) (Dumas, Wolf, Fisman, & Culligan, 1991). Interestingly, after controlling for group differences in perceived parenting stress, the level of maternal depression was no longer significantly higher. The depression appeared to be directly associated with the stresses of parenting challenging child behaviours, rather than symptomatology reflective of a discrete depressive disorder.

In a sample of 219 parents (141 mothers, 78 fathers) of children with ASD, Sharpley, Bitsika, and Efremidis (1997) found 13.2% of parents self-reported moderate depression and 5.9% reported severe depression. They also investigated anxiety with results showing 41.8% of parents self-reporting anxiety levels in the moderate range, 18.6% in the high anxiety range and 9.1% in the severe anxiety range. Overall, 81.9% of parents reported that they felt “stretched beyond their limits” multiple times per month as a result of their child’s behaviours, and 52.2% reported “feeling unable to cope”. A reduction in reported depression and anxiety was associated with access to respite care through an immediate family member who understood the child’s difficulties and needs. Respite care also led to an increase in parents’ perceived ability to parent their child’s challenging behaviours.
Self-report measures, including the Beck Depression Inventory, State-Trait Anxiety Inventory, Toronto Alexithymia Scale, and the Symptom Distress Check List (SCL-90) were used by Firat, Diler, Avci, and Seydaoglu (2002) to investigate anxiety, depression, alexithymia, and general psychological symptoms in 40 mothers of children with moderate to severe ASD and 38 mothers of children with a severe intellectual disability. Mothers of children with ASD had significantly higher levels of depression (72.5%) and anxiety (state and trait) (7.5%) compared to mothers of children with intellectual disabilities (44.7% and 5.3%, respectively). Mothers of children with ASD also reported higher psychopathologic somatisation than mothers of children with intellectual disabilities (40% versus 23.7%), obsessive-compulsive behaviours (37.5% versus 10.5%), anger-hostility (17.5% versus 0%), phobic anxiety (37.5% versus 7.9%), and paranoid thought (35% versus 10.5%). It is interesting to note the higher rates of somatisation and anger-hostility in parents of children with ASD, as these are two common forms of posttraumatic stress reactions (Kessler, Sonnega, Bromet, Hughes, & Nelson, 1995). Firat et al. concluded that clinicians should be aware of the need for the assessment of parents’ psychological well-being and that their presenting symptomatology may vary due to the nature of their child’s difficulties.

The use of gold standard clinical assessment in research investigating parent depression and anxiety is rare. Charmsil and Bathia (2010) overcame this limitation, using the Mini International Neuropsychiatric Interview to identify major depressive disorder and dysthymic disorder in 14.8% and 11.1%, respectively, in a sample of 27 caregivers of Thai children with ASD. Although a small regional sample, they were able to conclude that the prevalence rate of depressive disorders in the sample was higher than the general population. Research that utilises clinical assessment helps determine whether parents are not only experiencing an emotional reaction but also a disorder that requires treatment (Charmsil & Bathia, 2010).

Although these studies indicate the presence of depression and anxiety in some parents of children with ASD, there remains a significant gap in our knowledge. For example, the lack of reported child age ranges (e.g. Charmsil & Bathia, 2010) or a broad age range (e.g. 3–33 years of age; Sharpley et al., 1997) precludes consideration of the impact of developmental stages and the determination of whether psychological impairment in parents alters over the life course. Additionally, the types of challenging behaviours children exhibit which contribute to parent depression and anxiety are not clearly defined. A greater understanding of parent psychopathology would better inform appropriate support and/or treatment options for parents.

Grief

Although grief is not extensively researched in parents of children with ASD, qualitative research indicates that it is part of the parenting experience. Some parents have reported grieving over the loss of the child they expected to parent (O'Brien, 2007), their child’s delayed development, changes in the parent–child relationship, doubts about their parenting capacities and the loss of their own social relationships due to the demanding nature of parenting some children with ASD (Bitsika & Sharpley, 2004; Klauber, 1998; O’Brien, 2007).

Qualitative research investigating grief in parents of children with chronic illness indicates that uncertainty associated with chronic illness creates a situation whereby there is
no predictable end to the loss parents experience and a distinct lack of closure (George, Vickers, Wilkes, & Barton, 2006). This situation is thought to result in chronic sorrow which is characterised by pervasive and periodic sadness (Vickers, 2005). Parents of children with chronic illness have also reported specific events as being traumatic (such as the receipt of their child’s diagnosis) which exacerbated their grief (George et al., 2006). Although chronic sorrow may help further our understanding of the experience of parenting children with ASD, it also seems plausible to suggest that events perceived as traumatic by parents may also result in trauma-related symptomatology.

**Stress**

Parenting stress is one of the most frequently investigated constructs in family research aimed at capturing the psychological experience of parenting a child with ASD (Hayes & Watson, 2013). Parenting stress is defined as the experience of distress or discomfort that results from demands associated with the current and future role of parenting (Deater-Deckard, 1998).

A meta-analysis of parenting stress found that parents of children with ASD report higher levels of parenting stress compared with families of children with Down syndrome (Eisenhower et al., 2005), cystic fibrosis (Bouma & Schweitzer, 1990), cerebral palsy (Blacher & McIntyre, 2006), and intellectual disability (Blacher & McIntyre, 2006). The effect sizes for the above comparisons were large, suggesting that for some parents of children with ASD, parenting stress may be a clinically significant experience, which increases the risk for depression and poor overall quality of life and well-being (Hayes & Watson, 2013).

Foody, James, and Leader (2014) have reported physiological markers of elevated stress in parents of children with ASD. They compared parenting responsibility, distress, anxiety, depression, cortisol, alpha-amylase, and cardiovascular activity in 19 mother–father dyads of children with ASD. Parents had lower than average morning cortisol levels, suggesting stress effects on the hypothalamic–pituitary–adrenal axis. An abnormal cardiovascular activity was also identified, with fathers showing significantly elevated blood pressure and heart rate variability than mothers, and mothers showing reduced heart rate variability. This finding is of particular concern given that high blood pressure and low heart rate variability have been found to independently predict cardiovascular mortality (Kario & Pickering, 2000). Foody et al. recommend parents of children with ASD may benefit from routine health screening (particularly adrenal and cardiovascular) as well as involvement in stress reduction interventions.

There is a dearth of studies investigating a clinical conceptualisation of the symptomatology parents exhibit when reporting elevated parenting stress. A greater understanding of the symptomatology associated with elevated parenting stress would aid in the development of targeted interventions to prevent or reduce stress.

**A traumatic stress framework**

A review of the literature identified child behavioural challenges that are associated with high rates of mental health difficulties and concerning levels of parenting stress. Some of the child behaviours involved actual or threatened serious injury (e.g., SIBs) and death (e.g., elopement). This begs the question, therefore, of whether some
parents who experience these events may then exhibit symptomatology that could be best explained by a traumatic stress framework.

Over time, the diagnostic focus for trauma in subsequent editions of the Diagnostic and Statistical Manual of Mental Health Disorders (DSM) has shifted from the adaptive capacity of the individual to exposure to a traumatic or stressful event which is explicitly defined as part of diagnostic Criterion A for Posttraumatic Stress Disorder (PTSD). In the DSM-III, traumatic or stressful events were defined as "outside the range of usual human experience" (American Psychiatric Association, 1980, p. 236). With each new edition of the DSM, the concept of Criterion A has evolved and the events considered traumatic have become increasingly specific.

The most recent conceptualisation of Criterion A in the DSM-5 is exposure to actual or threatened death, serious injury, or sexual violence either through direct experience, witnessing the event in person, learning that the event occurred to a close family member or friend, or through repeated or extreme exposure to aversive details of the event (American Psychiatric Association, 2013). Events that qualify as traumatic are defined in detail in the diagnostic features of PTSD (e.g., physical assault, natural or man-made disasters, suicide of a close relative or friend, or serious accident). Following exposure to a traumatic event the individual may then exhibit symptomology identified in the DSM-5 as Criterion B-E for a trauma-related diagnosis (i.e., intrusion symptoms, avoidance of associate stimuli, negative alterations in mood/or cognition, and alterations in arousal and reactivity).

PTSD and Acute Stress Disorder are the only DSM disorders that mandate specific events as the aetiological foundation or precipitant. Over the past decade there has been an ongoing debate regarding the utility of specifying the types of events that are considered aetiological. The assumption that exposure to a specific traumatic stressor/s is the primary cause of a unique set of stress response symptoms is problematic as stressors vary along a number of dimensions including magnitude, complexity, frequency, duration, predictability, and controllability (Weathers & Keane, 2007).

Trauma-related symptomatology amongst parents of children with ASD

It is proposed that some parents of children with ASD would be exposed to a DSM-5 PTSD Criterion A event (e.g., child engaging in high risk SIBs). As a consequence, for some parents, this may lead to the development of trauma-related symptomatology consistent with a trauma-related diagnosis. Rates of trauma-related clinical diagnoses such as PTSD and Acute Stress Disorder amongst parents of children with ASD remain unknown. The lack of a reported prevalence is concerning and there may be several reasons for this. Parents may be low seekers of professional help for themselves (due to an exclusive focus on their child's management and well-being) or, they may be more commonly diagnosed with mood or anxiety disorders which do not share with PTSD the additional criterion of a defined traumatic event (Kilpatrick, Resnick, & Acierno, 2009). Although some parents may indeed meet the clinical criteria for mood and/or anxiety disorders, there remains the possibility that, in some cases, a traumatic stress framework may provide a more valid clinical representation of their presentation and parenting experience.

Seltzer et al. (2010) investigated reports of chronically elevated stress levels in mothers of children with ASD using physiological measures of stress. They examined the association between child behaviour problems and maternal salivary cortisol amongst 86
mothers of adolescents or adults (aged 18 to 53; 79% male) with ASD with whom they co-resided. Their findings demonstrated that mothers of children with ASD had a profile of hypothalamic–pituitary–adrenal axis hyperactivity as compared to the normative patterns manifested by mothers with similar aged children who did not have a disability. No significant differences in cortisol levels were found between mothers of children with ASD and mothers of children with ASD and an intellectual disability. Mothers’ experience of both acute and chronic stress was linked to their child’s behavioural challenges. It was concluded that the cortisol profile these mothers exhibited was similar to findings in other populations who were experiencing chronic stress, including combat soldiers (Yehuda, Boisneau, Lowy, & Giller, 1995), Holocaust survivors (Yehuda et al., 1995), and individuals suffering from PTSD (Yehuda, 1997).

To our knowledge, only one study has been published to date that investigated whether elevated stress in parents of children with ASD could be conceptualised within a traumatic stress framework, which the authors referred to as “posttraumatic stress symptoms” (PTSS) (Casey et al., 2012). The term PTSS refers to sub-clinical levels of PTSD (i.e. diagnostic criteria B–G only). Casey et al. surveyed 256 parents (245 mothers) to investigate PTSS occurring in association with the event of learning of their child’s ASD diagnosis. Based on the current PTSD criterion A in the DSM-5, receiving your child’s clinical diagnosis is not considered a traumatic stressor, however, results revealed that 20% of parents reported moderate to high levels of PTSS as a result of experiencing this event. Commonly endorsed trauma-related criteria included intrusion or re-experiencing of the diagnosis (e.g. thinking about the event when not intending to), avoidance (e.g. staying away from reminders of the diagnosis), and hyperarousal (e.g. constant feeling of being easily startled). Although these parents did not meet the full criteria for a DSM-IV-TR diagnosis of PTSD they reported experiencing severe negative reactions representative of trauma-related symptomatology, which the authors identified as PTSS. A limitation was the use of anonymous online self-reports. The use of self-report measurement compared to structured clinical interviews limits the capacity to examine more detailed phenomenology that may distinguish, for example, between intrusive recollections associated with a traumatic event versus rumination associated depression. Additionally, the majority of parents were mothers and thus findings may not represent fathers’ experiences. Nevertheless, one in five parents reported experiencing PTSS. The existence of PTSS may compromise parents’ efficacy as caregivers and negatively affect their child’s behaviour and treatment (Cabizua, Marques-Portella, Mendlowicz, Coutinho, & Figueira, 2009).

Further investigation, with gold standard clinical measures, is warranted to establish whether a subpopulation of parents with children with ASD exhibit psychopathology consistent with a DSM-5 PTSD diagnosis. A positive finding in this regard would inform not only an evolving understanding of trauma-related psychopathology but, importantly, how best to support this unique population in terms of specialist mental health services.

The presence of traumatic stress and implications for treatment

The Australian Guidelines for the Treatment of Adults with Acute Stress Disorder and PTSD recommend trauma-focused cognitive behaviour therapy (TFCBT) as the best practice intervention to achieve optimal outcomes (Australian Centre for Posttraumatic
PTSS in parents of children with ASD

Mental Health [ACPMH], 2013). Studies examining the effectiveness of non-trauma-focused interventions (e.g., anxiety management, stress inoculation training) found that these interventions were not as effective as TFCBT when used in isolation (ACPMH, 2013).

Given the dearth of research investigating traumatic stress amongst parents of children with ASD, clinicians are unlikely to consider and/or screen for trauma symptomatology when working with parents who present for support and/or intervention. Thus there is a need for further research that investigates the validity of adopting a traumatic stress framework to encapsulate some parenting experiences and resulting symptomatology.

Conclusion

The challenge for researchers and clinicians is to better determine how elevated stress levels in this unique population are best conceptualised from a diagnostic perspective, and consequently, how this may inform optimal clinical management. The current conceptualisation of the parenting experience and high levels of stress associated with parenting some children with ASD has predominately accumulated from self-reports and symptom checklists. There has only been one study to date which has explored a clinical conceptualisation of traumatic stress, reporting evidence of PTSS in parents after receiving their child’s ASD diagnosis (Casey et al., 2012). Future research methodologies that incorporate gold standard diagnostic assessment will assist in an investigation of whether trauma-related psychopathology is a valid clinical representation of the parenting experiences and mental health presentations of some parents of children with ASD. If trauma-related psychopathology was identified in a subpopulation of these parents, there would be significant implications for optimising clinical practice, including consideration for trauma screening measures and interventions that draw from current guidelines for the treatment of trauma.

References


PTSS in parents of children with ASD


Chapter 5: Qualitative investigation of traumatic stress in parents of children with ASD

The paper presented in the previous chapter (Stewart, McGillivray, Forbes, & Austin, 2016) identified that one of the limitations in the current literature is that our knowledge of stress has been derived primarily from online self-report measures and symptom checklists. Furthermore, although this limitation applies to the seminal study of PTSS by Casey et al. (2012), it remains the first of its kind to explore the paradigm of PTSS in parents of children with ASD. Casey et al. have made a significant contribution to the ASD literature by reconceptualising parenting stress within a PTSS framework that is more compatible with a clinical interpretation of parent mental health. Although parents were not formally assessed for PTSD, 20% of their sample endorsed moderate to high levels of posttraumatic stress symptoms. The presence of trauma symptomatology has important implications for understanding this population and optimising clinical intervention.

The use of a clinical framework to further our understanding of parenting stress has also received empirical support from studies that have utilised physiological measures (e.g., parent saliva samples). Foody et al. (2014) and Seltzer et al. (2010) demonstrated that parents of children with ASD experience unusually heightened stress levels that produce cortisol profiles comparable to individuals who have been exposed to PTSD Criterion A traumatic stressors. Seltzer et al. found a positive association between challenging child behaviours and unusual cortisol profiles.

Although the more prevalent diagnoses amongst this population of mood and anxiety disorders may be valid in many cases, the core features of these two...
diagnoses also form part of the diagnostic criteria for PTSD. The challenge for future research is to not only overcome the limitations identified in the previously presented literature review, but to also differentiate between these diagnoses.

One of the aims of the following paper (Stewart, Knight, McGillivray, Forbes, & Austin, *in press*) was to overcome the limitations of online self-reports and checklists by adopting a qualitative method. Parents of children with ASD were invited to attend focus groups to share stories about the types of challenging behaviours they found most stressful to parent. Participants were not informed of the researchers’ interest in traumatic stress, nor was the word ‘trauma’, ‘PTSD’ or any related language used in order to avoid priming (and biasing) the parent reports. The aim was to establish whether parents would spontaneously report events and symptomatology that may be considered consisted with PTSS or PTSD.
Paper 2

# Authorship Statement

1. **Details of publication and executive author**

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<th>Title of Publication</th>
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<tr>
<th>Name of executive author</th>
<th>School/Institute/Division if based at Deakin, Organisation and address if non-Deakin</th>
<th>Email or phone</th>
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2. **Inclusion of publication in a thesis**

| Is it intended to include this publication in a higher degree by research (HDR) thesis? | Yes | If Yes, please complete Section 3 If No, go straight to Section 4. |

3. **HDR thesis author’s declaration**

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<th>Name of HDR thesis author if different from above. (If the same, write “as above”)</th>
<th>School/institute/Division if based at Deakin</th>
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<td>Michelle Stewart</td>
<td>School of Psychology</td>
<td>Traumatic stress in parents of children with autism spectrum disorder</td>
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If there are multiple authors, give a full description of HDR thesis author’s contribution to the publication (for example, how much did you contribute to the conception of the project, the design of methodology or experimental protocol, data collection, analysis, drafting the manuscript, revising it critically for important intellectual content, etc.)

Conceptual development of study, ethics application, recruitment, facilitator of focus groups, data management and analysis, drafting of manuscript, revisions, principal author.

I declare that the above is an accurate description of my contribution to this paper, and the contributions of other authors are as described below.

Signature and date: 30th July 2016

4. **Description of all author contributions**

<table>
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<tr>
<th>Name and affiliation of author</th>
<th>Contribution(s) (for example, conception of the project, design of methodology or experimental protocol, data collection, analysis, drafting the manuscript, revising it critically for important intellectual content, etc.)</th>
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<tr>
<td>Michelle Stewart</td>
<td>Design of methodology, ethics application, recruitment, facilitator of focus groups, data management and analysis, drafting the manuscript, revisions, principal author.</td>
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<tr>
<td>A/Prof David Austin</td>
<td>Design of methodology, facilitator of a focus group, review and feedback for manuscript.</td>
</tr>
<tr>
<td>Prof Jane McGilivray</td>
<td>Review and feedback for manuscript.</td>
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<tr>
<td>A/Prof Tess Knight</td>
<td>Design and methodology, data analysis, review and feedback for manuscript.</td>
</tr>
<tr>
<td>Prof David Forbes</td>
<td>Review and feedback for manuscript.</td>
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5. Author Declarations

I agree to be named as one of the authors of this work, and confirm:

i. that I have met the authorship criteria set out in the Deakin University Research Conduct Policy,

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6. Other contributor declarations

I agree to be named as a non-author contributor to this work.

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* if an author or contributor is unavailable or otherwise unable to sign the statement of authorship, the Head of Academic Unit may sign on their behalf, noting the reason for their unavailability, provided there is no evidence to suggest that the person would object to being named as author.

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If the publication is to be included as part of an HDR thesis, a copy of this form must be included in the thesis with the publication.
Through a trauma-based lens: A qualitative analysis of the experience of parenting a child with an autism spectrum disorder

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Author note: No funding or conflict of interest was involved in this study.
Abstract

Background Although parents of children with autism spectrum disorder (ASD) exhibit high levels of parenting stress, minimal research has examined the type of stress they experience. Understanding parenting stress is critical as the effects are not limited to the parent. The aim of this study was to investigate the validity of conceptualising parenting stress within a traumatic stress framework.

Method Twelve mothers participated in focus groups, which were recorded and transcribed verbatim. Interpretative Phenomenological Analysis was used then researchers examined for spontaneous reporting of DSM-5 defined traumatic stressors and trauma symptomatology.

Results Forty percent of mothers experienced traumatic stressors and trauma-related symptomatology. Sixty percent of mothers did not report traumatic stressors but reported trauma-related symptomatology regardless.

Conclusions The use of a traumatic stress framework to conceptualise some parenting experiences was supported. This finding has important implications for the development of interventions to prevent or reduce stress.

Key words: autism; ASD; mothers; behaviours; stressors; trauma
Autism spectrum disorder (ASD) is a lifelong, complex developmental disorder that has no clear aetiology, cure, or standard of medical treatment (Woodgate, Ateah, & Secco, 2008). Recent prevalence rates indicate ASD affects approximately 1.47% of the world’s population (Centers for Disease Control and Prevention, 2014). In Australia, an estimated 0.5% of individuals have ASD, with males being four times more likely than females to have an ASD diagnosis (Australian Bureau of Statistics, 2012). The ongoing and significant parenting challenges associated with raising a child with ASD have been identified as contributing to parenting stress.

Parenting stress, defined as the experience of distress or discomfort resulting from demands associated with parenting (Deater-Deckard, 1998), has been well documented by researchers investigating the impact of parenting children with disabilities (e.g., Casey et al., 2012; Eisenhower, Baker, & Blacher, 2005). Findings demonstrate that different disability diagnoses present specific strengths and challenges that influence parenting stress (Dykens & Hodapp, 2001). A meta-analysis of parenting stress found that parents of children with ASD typically report higher levels of parenting stress compared with families of children with Down syndrome (Eisenhower et al., 2005; Griffith, Hastings, Nash, & Hill, 2010; Hamlyn-Wright, Draghi-Lorenz, & Ellis, 2007), cystic fibrosis (Bouma & Schweitzer, 1990), cerebral palsy (Blacher & McIntyre, 2006), and intellectual disability (Blacher & McIntyre, 2006; Griffith et al., 2010). The effect sizes for the above comparisons were large ($d = 0.35–1.48$), suggesting that for some parents of children with ASD, parenting stress may be a clinically significant experience, which increases risk of depression and poor overall wellbeing (Hayes & Watson, 2013).

A significant challenge that has been shown to contribute to parenting stress in parents of children with ASD is the frequency and severity of their child’s
externalising behaviours. These behaviours include anti-social or aggressive
daviours (Matson & Rivet, 2008), inappropriate social behaviours such as faecal
smearing and chronic screaming (Oberleitner, Ball, Gillette, Naseef, & Stamm,
2006), ‘meltdowns’ (McClintock, Hall, & Oliver, 2003), elopement (Anderson et al.,
2012), and self-injurious behaviours (Duerden et al., 2012). The severity of core
ASD symptoms including social deficits and restricted/repetitive behaviours have
also been linked to elevated parenting stress (Davis & Carter, 2008). Atypical
behaviours reported in a substantial minority of children including suicidal ideation
and attempts (Mayes, Gorman, Hillwig-Garcia, & Syed, 2013) have also been
identified by parents as significantly challenging behaviours leading to parenting
stress.

Social factors have been implicated in contributing to parenting stress. Negative
public attitudes towards disability may lead parents to experience their child being
socially devalued or disrespected (Green, Davis, Karshmer, Marsh, & Straight, 2005)
and their own parenting ability coming under scrutiny by the general public (Gray,
1993). Mothers of children with ASD have reported frequently encountering
insensitive reactions from the public, including criticism and antipathy when their
child engages in behaviour deemed unacceptable by the societal context: “You
shouldn’t even let her out in public. You should keep kids like that at home” (Neely-
Barnes, Hall, Roberts, & Graff, 2011, p. 214). Mothers can be socially debilitated by
the emotional consequences of such experiences (Green et al., 2005), increasing the
likelihood of social isolation or withdrawal (Myers, Mackintosh, & Goin-Kochel,
2009), lowered self-image, and depression (Green et al., 2005).

Although contributing factors to parenting stress are frequently discussed throughout
the literature, there is a dearth of proposed clinical frameworks to conceptualise this
phenomenon. A clinical framework to identify the symptomatology associated with significantly elevated stress would aid in the development of targeted interventions to prevent or reduce this experience.

**Traumatic stress**

Over time, the diagnostic focus for trauma in the Diagnostic and Statistical Manual of Mental Health Disorders (DSM) has shifted from the adaptive capacity of the individual to exposure to a traumatic or stressful event, which is explicitly defined as part of diagnostic Criterion A. The most recent conceptualisation of Criterion A for trauma-related diagnoses in the DSM-5 is exposure to actual or threatened death, serious injury, or sexual violence either through direct experience, witnessing the event in person, learning that the event occurred to a close family member or friend, or through repeated or extreme exposure to aversive details of the event (American Psychiatric Association, 2013). Following exposure to a traumatic event the individual may exhibit symptoms identified in the DSM-5 as Criteria B–E for a trauma-related diagnosis (intrusion symptoms, avoidance of associated stimuli, negative alterations in mood and/or cognition, and alterations in arousal and reactivity). The DSM-5 trauma-related diagnoses are Posttraumatic Stress Disorder (PTSD) and Acute Stress Disorder. Acute Stress Disorder is distinguished from PTSD by restriction of symptoms to a duration of three days to one month following exposure to a traumatic event (American Psychiatric Association, 2013). It is proposed that some parents of children with ASD would be exposed to events specified in Criterion A (e.g., child engaging in self-injurious behaviours) and may therefore experience trauma-related symptomatology. Rates of trauma-related clinical diagnoses such as PTSD and Acute Stress Disorder in parents of children with ASD remain unknown.
PTSS in parents of children with ASD

Seltzer and colleagues (2010) investigated reports of chronically elevated stress levels in mothers of children with ASD by examining the associations between child behaviour problems and maternal salivary cortisol. Mothers of children with ASD had a profile of hypothalamic-pituitary-adrenal axis hypoactivity as compared with normative patterns manifested by mothers with similar-aged children who did not have a disability. The mothers experienced both acute and chronic stress, which was related to their child’s behaviour. The researchers concluded that the profile these mothers exhibited was similar to findings in other populations who were experiencing chronic stress, including combat soldiers (Yehuda, Boisoneau, Lowy, & Giller, 1995), Holocaust survivors (Yehuda et al., 1995), and individuals suffering from PTSD (Yehuda, 1997). Thus not only do mothers report high levels of psychological stress, but also appear to present with a physiological stress profile characteristic of individuals who are responding to clinical trauma.

To our knowledge, only one study has been published that investigated whether elevated stress in parents of children with ASD could be conceptualised within a clinical framework, which authors referred to as posttraumatic stress symptoms (PTSS; Casey et al., 2012). The term PTSS is used to refer to sub-clinical levels of posttraumatic stress disorder (PTSD; i.e. diagnostic criteria B–G). Casey et al. surveyed 256 parents (245 mothers) to investigate PTSS occurring in association with learning of their child’s ASD diagnosis. Although receiving a child’s diagnosis is not considered as a traumatic event in the DSM-IV-TR, results revealed that 20 percent of parents reported moderate to high levels of PTSS as a result of experiencing this event. Endorsed trauma-related criteria included intrusion or re-experiencing of the diagnosis (e.g., thought about event when did not intend to),
PTSS in parents of children with ASD

avoidance (e.g., staying away from reminders of the event), and hyperarousal (e.g., constant feeling of uneasiness or being easily startled). Although parents did not meet the full criteria for a DSM-IV-TR diagnosis of PTSD, they reported experiencing severe negative reactions representative of trauma-related symptomatology. Given the existence of PTSS has been proposed to compromise parents’ efficacy as caregivers (Cabizuca, Marques-Portella, Mendlowicz, Coutinho, & Figueira, 2009), further research is warranted.

Aim

The primary aim of the current study was to investigate whether trauma-related symptomatology was prevalent in a subpopulation of mothers of children with ASD. To explore this aim we observed whether mothers spontaneously reported experiencing traumatic events and/or trauma-related symptomatology consistent with a DSM-5 trauma-related diagnosis such as PTSD. A positive finding in this regard would support consideration for a traumatic stress framework, which in turn, would have significant implications for first-line treatment and optimising support for mothers.

Method

Informed consent

Ethics approval for all aspects of the study was obtained from the Deakin University Human Research Ethics Committee, Australia. Informed written consent was obtained prior to participants taking part in one of the focus groups. Participants were informed that any published research would use pseudonyms to protect their confidentiality.
**Study design**

A phenomenological approach was used to address the research aims. Patton (1990) described phenomenological inquiry as the exploration of “what people experience and how they interpret the world” (p. 69). This approach was chosen as it enquires into participants’ lived experiences and their understanding of the phenomenon under investigation. It was important to understand how mothers experience parenting a child with ASD to enable us to examine their experiences in relation to trauma-based symptomatology as operationalised in the DSM-5. We used focus groups rather than one-on-one interviews as we expected that the interaction between group members would encourage richer dialogue resulting in a wider range of themes discussed amongst mothers, with the clinician taking a facilitative role (Grudens-Schuck, Allen, & Larson, 2004).

**Participants**

Participants were purposefully recruited through ASD websites, ASD forums, and specialised schools. To be included in the study, the parent had to have at least one biological child aged between 6 and 18 years who had a formal ASD diagnosis. Evidence of formal diagnosis by a registered paediatrician or psychologist was required for inclusion. Parents who identified with the experience of raising a child with ASD who exhibited challenging behaviours were invited to contact the first author (M.S) to learn more about the study. Although both mothers and fathers were sought, no fathers were successfully recruited. Twelve mothers participated. If the mother had more than one child diagnosed with ASD, they were asked to speak about their parenting experiences associated with the child who presented the most challenges. The mean age of the children mothers spoke of was 10.89 years (standard deviation ($SD = 3.84$ years). There was a predominance of male children in the
sample (11 boys, 1 girl), which was not unexpected given ASD prevalence amongst males is several times that of females (Australian Bureau of Statistics, 2012). Seven of the mothers reported one child diagnosed with ASD, four reported two children diagnosed with ASD, and one mother reported three children diagnosed with ASD. Seven of the mothers were married to their child’s biological father, one was in a de facto relationship, and four identified as single mothers. Three of the mothers worked part-time, one was studying, and the remaining eight identified as full-time carers and/or stay at home mothers. After conducting three focus groups, no new information relevant to the study’s purpose emerged, thus it was determined that data saturation had been achieved.

Procedure

Mothers were invited to attend a focus group, comprised of three to five participants. As each mother arrived to the agreed location she gave the facilitator a signed consent form and was invited to partake in refreshments. Each focus group was approximately 60 to 90 minutes in duration. The first group was co-facilitated by the first author (provisional psychologist) and last author (registered psychologist), and the remaining two groups were facilitated by the first author.

Facilitators utilised an interview guide they had developed which included a list of primary open-ended questions to be asked during the focus groups. To avoid biasing discussion, facilitators did not use the word ‘trauma’ or variations on this language. The primary questions included: (1) what was your experience of receiving your child’s ASD diagnosis? (2) What are some of the most challenging behaviours you have encountered raising your child? (3) How do these challenges impact you? and (4) What self-care strategies do you engage in? On the basis of mothers’ responses, facilitators used probing follow-up questions to clarify comments and elicit in-depth
explanations. An example of such a probing question was, “Can you tell me a little more about your experience of that?”

Prior to the focus groups and at the conclusion of the focus groups the facilitator provided details of relevant telephone counselling services (e.g., Lifeline) and invited participants to contact the researchers directly if they had any concerns or wished to discuss the focus groups. They were also given a gift voucher to the value of $AU20 for their participation. The focus groups were audio recorded and field notes detailing observations were documented throughout the session. The audio was transcribed verbatim, except for names and identifying information, which were replaced with pseudonyms.

**Data analysis**

Interpretative phenomenological analysis was used to explore how participants perceived and made sense of the challenges associated with their parenting experience. While the purpose of interpretative phenomenological analysis is to gain an insider perspective, it is also acknowledged that the researcher is the primary analytical instrument. Rather than the researcher’s beliefs being seen as biases to be eliminated, they are considered necessary for interpreting the experience of other individuals (Fade, 2004). Such interpretation requires embracing a set of well-developed themes that are systematically linked through related statements (Smith & Osborn, 2008). The researchers were constantly aware of the trauma lens with which they approached the study.

The development of the themes emerging from the data was conducted according to interpretative phenomenological analysis (Patton, 1990) whereby transcripts from the focus groups were initially read several times to gain a sense of the overall meaning mothers ascribed to their parenting experience. The data were then analysed for
trauma-related themes, as identified by PTSD diagnostic criteria in the DSM-5, and coded by the first author according to those themes. A second independent coder was used to analyse and code one of the three transcripts using PTSD diagnostic criteria. Coding was consistent across both interpreters. This process was overseen by the last author. Once completed, the researchers met to discuss possible biases in interpretation, conceptualisations of themes, and the identification of traumatic events and symptomatology to ensure consensus.

**Results**

Forty percent of mothers (five mothers) spontaneously reported experiencing DSM-5 defined traumatic events, and symptomatology consistent with clinical trauma. Of these five mothers, three had one child diagnosed with ASD and two had two children diagnosed with ASD. Mothers who did not report DSM-5 defined traumatic stressors (e.g., experience of receiving child’s ASD diagnosis, constant faecal smearing) still reported experiencing trauma-related symptomatology as a result of their parenting experiences. Results are presented under subheadings aligned with DSM-5 trauma criteria.

**Criterion A: Traumatic stressors**

This criterion refers to exposure to actual or threatened death, serious injury, or sexual violence, either through direct experience, witnessing the event in person, learning that the event occurred to a close family member or friend, or through repeated or extreme exposure to aversive details of the event (American Psychiatric Association, 2013). Five mothers spoke about physically restraining their child to protect them from injuring himself or herself, the mother, a sibling, or a stranger:
“It’s a matter of putting my own safety second, as you’ve got to get in there, pin them down, and try to calm them down.” These experiences involved exposure to direct actual or serious injury: “Sebastian 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” and “I used to restrain Jacob 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.”

Mothers also described direct threatened serious injury: “Marcus nearly broke my arm because he was so strong”, “between three or four hours I’d have to restrain Lucas or he would beat the crap out of me”, and “at four years of age Jacob was throwing televisions and chairs across the room.” Mothers identified their child’s behaviour as a potential threat to others: “John’s behaviour is too unpredictable… the other kids are in danger”, “…Holding Marcus down so he didn’t attack his younger brother”, and needing to be within two feet of one child at all times to avoid him “lashing out at strangers.” One mother reflected on her experience of restraint: “Restraining my child is devastating… Holding him and being physical with him, despite knowing if you don’t he is going to harm himself and no one wants to watch their child smash their head.”

Although mothers reflected on single events of restraint in detail, they communicated that these events were not singular in nature but recurrent. One mother remarked that her parenting journey “tests every call in your body every day; even when it’s a good day. It’s flight or fight all the time.” Language that stood out during these stories included “fear”, “guilt”, “anger”, “helplessness”, and “hopelessness.”

Three mothers raised concerns about their child’s safety as a result of elopement: “Next thing you know John has gone missing at the park. I’m thinking paths, roads…"
there’s everything, because he’s an absconder.” Two mothers spoke about their son’s lack of road safety and having to be “hypervigilant” around roads because “he will run across the street in two seconds and he will get killed” and “…Sebastian is on a road and he is going to try and run on the road, and no road sense could get him hit by a car.”

Four mothers spoke of their child’s self-harming behaviours, which arose in the context of their child having a meltdown or experiencing anxiety. One mother said she had to be vigilant of “Jacob trying to throw himself through windows” and another mother said, “he started self-harming (early in school) and we just decided to home school.” Head banging was also an issue raised by three mothers, with concerns about safety, as “John would have head banging tantrums into the concrete” and:

Sebastian can’t talk, so he can’t say what he needs. I don’t know what is going through his head when he is having his meltdown. It must be horrendous, because he is hitting his head so hard that…. And he’s prepared to self-harm.

Mothers who were parenting non-verbal children also identified communication difficulties as a challenge. One mother recounted her child arriving home from school crying and angry with the “worst bruises you’ve ever seen.” Silently crying she spoke of feeling “helpless and fearful” and of feeling “unable to fulfil my need as a mother” as she did not know how he had sustained the injuries and could not “fix it.”
Criterion B: Intrusive symptoms associated with a traumatic event

This criterion refers to the presence of one or more symptoms that occur after a traumatic event and include recurrent distressing memories, distressing dreams, dissociative reactions, prolonged periods of psychological distress at exposure to cues, and marked physiological reactions to cues (American Psychiatric Association, 2013). Most mothers appeared to associate recurrent distressing memories with specific episodes of self-injury and restraint. For example, one mother spoke of an electricity outage that led her son to experience a meltdown. She recalled him being at risk of serious injury, as he kicked in the walls of the house and screamed loudly for such an extended period of time that she thought someone would phone the police. She reported ongoing thoughts about this event that caused her to experience anxiety and distress about another possible power outage. The following nights after this event she reported:

Continually waking up and it felt like my heart had stopped. I had to get up and check the light switches to make sure the power was still on because if it happened again he will hurt himself; he’ll either hit his head so hard or kick the walls in.

Although not identified in the DSM-5 as a traumatic event, nine mothers described the experience of receiving their child’s diagnosis as a distressing memory that was later triggered by certain events: “All of a sudden you are dragged back to that diagnosis day… It just all comes flooding back… It’s a physical experience… It’s almost like a cold hand on my stomach.” Triggers that led mothers to “re-live” this experience included having to provide evidence of the diagnosis for funding, talking about the diagnosis with others, watching their child engage in life-threatening
behaviours, and their child’s negativity towards their diagnosis. One mother reported her child saying “I wish I could cut the Asperger’s out of my brain… Why do I do such bad things? I must be so hard to love” and “he did not want to live like this for the rest of his life, he said ‘this is all just too hard’. When experiencing these memories mothers reported feeling strong emotions, physiological reactivity (e.g., increased heart rate, sweaty palms, flushing), and needing to remove themselves from the environment and other people.

**Criterion C: Avoidance of stimuli associated with traumatic event**

This criterion refers to effortful avoidance of thoughts, memories or feelings closely associated with the traumatic event and/or avoidance of external stimuli that arouse distressing thoughts or feelings (American Psychiatric Association, 2013). The avoidance of feelings closely associated with a traumatic event was evident. Six mothers expressed a sense of detachment from their emotions in order to “survive” when their child was self-harming and/or required restraint to protect them: “I go into like this survival mode, and you shut off your emotions”, “you go into zombie mode”, and “I feel really detached from it.” After these experiences mothers spoke of needing to “get out of the house” to “go for a drive” or to isolate themselves in a bedroom and put on loud music through their headphones and “pretend to scream.” These actions may be representative of avoiding external reminders of the event (e.g., the child, the room the event took place) or could be an emotional regulation mechanism.

Although not recognised as a traumatic event in the DSM-5, mothers spoke about the difficulties they experienced processing their emotions around the period of their child’s diagnosis due to fears it would impair their ability to function as a parent:
“You cut a deal with your own emotions” and “you’re a mother, you can’t just stop.” The theme of not processing emotions was evident across other stories, which spanned many years of their children’s lives.

Criterion D: Negative alterations in cognitions and mood associated with a traumatic event

This criterion refers to the presence of two or more symptoms including dissociative amnesia, exaggerated negative beliefs, distorted cognitions about cause or consequences of event (self-blame), negative emotional state, markedly diminished interest or participation in significant activities, feelings of detachment from others, and an inability to experience positive emotions (American Psychiatric Association, 2013). When mothers were sharing parenting challenges facilitators observed a negative shift in their presentation, including sadness, anxiety, and a flat or depressive affect. The words “depressing” and “anxiety” were commonly used, particularly when speaking of physical restraint. Marcus’ mother described the “emotional upheaval after these moments” and trying “not to get into that space of I don’t care about anything… I can quite easily fall into that space of despair and hopelessness.” Sebastian’s mother became quite emotional when discussing times she had restrained her son:

It’s just… and that’s what breaks my heart. Is that sort of stuff that you deal with everyday…It’s devastating. Absolutely devastating having to restrain your child. It’s… Really hard. I’m sorry (crying).
Six mothers shared that they had been prescribed anti-depressants shortly after their child was diagnosed. One mother reported her GP telling her she would likely be on anti-depressants for the rest of her life. One of these mothers spoke of trying to stop taking anti-depressants but experiencing “severe depression and (being) unable to cope.” She tearfully elaborated:

You know, I’ll be in the car… And having my son in the car driving somewhere with me is protective, because if he is not in the car… I start thinking about things to crash into.

The way three mothers spoke about their son’s ASD diagnosis indicated ongoing distorted cognitions resulting in self-blame. For example:

I don’t think I’m a victim. I feel that my son… My son is a victim of me. I logically know it’s not my fault, I know. I logically know I shouldn’t feel guilty. It’s a combination of bad genes and bad luck… But you lie there thinking… Was it something I ate while I was pregnant? Was there something I did while he was a newborn? It’s my fault somehow.

**Criterion E: Marked alterations in arousal and reactivity associated with a traumatic event**

This criterion refers to the presence of two or more symptoms including irritability, self-destructive behaviour, hypervigilance, exaggerated startle response, problems with concentration, and sleep disturbances (American Psychiatric Association, 2013). Mothers who reported difficulty managing challenging behaviours on a daily basis
spoke of the need to be on alert in the event they needed to intervene. Three mothers referred to “rages” or “meltdowns”, where their child would go from “zero to ten” within seconds, requiring immediate intervening. Four mothers referred to themselves as existing in a continuous “hypervigilant” state: “It’s like flight or flight 100% of the time” and “you’re always thinking… on edge.” One mother explained “it’s just a matter of catching it before it happens (physical aggression), because it can be really quick.” She then became emotional when recounting a recent outing where she was unable to restrain her son before he “crash tackled a three or four year old to the ground, horrifying the parents.” She concluded by saying, “I can’t go out just by myself with Marcus anymore.” Another mother spoke of being hypervigilant about triggering a meltdown: “For a very long time I was on eggshells around him, trying not to set him off.”

Mothers who reported feeling hypervigilant also spoke of sleep disturbances and irritability towards others at times: “I have pretty bad insomnia”, “I sleep four hours a night if I’m lucky”, and “there are times when I wake up in the middle of the night and I’m stressing about something that may or may not happen with him in the morning.” Another mother reflected on her irritability shortly after her child was diagnosed:

I’m an extremely placid person and yet I was so angry. Extremely angry and just set off like that! At the lowest point I was brushing my child’s hair so hard and after I was in tears and thought to myself that this is child abuse. What the hell is wrong with me? Oh it’s that I can’t cope right now.
**Criterion F: Duration of the disturbance is more than 1 month**

Six mothers identified the challenging behaviours they were parenting changed in level of frequency and intensity, but that they were ongoing behaviours, and at times “unrelenting.” Children’s hormones were identified as causing fluctuations in challenging behaviours and as children aged new challenges arose. Two mothers reported their child as challenging when younger, but in more recent years their most difficult behaviour had significantly decreased.

**Criterion G: The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning**

Two mothers said they were unable to work as they were “on call every day for the school” in the event something happened. In relation to being a full-time carer, a mother said: “You’re really isolated. The only conversations you do have are with professionals.” Mothers spoke about carers’ allowance being their main source of income, which was “very tough” and limited their ability to engage in social activities they enjoyed (e.g., going out for coffee, buying a book).

Feeling socially isolated due to others not understanding ASD was a common theme: “When we started to share our diagnosis we were totally ostracised. It was terrible, like if you were around my child you might catch it.” Other mothers said: “If my friends ask what I’m up to and if I say I have the boys they say they will catch me another weekend” and “not even my brother and sister-in-law will have us over because he has had a meltdown in their home and has broken toys and sworn.”

Challenging behaviours or meltdowns appeared to be significant contributing factors that impaired social interactions with family: “They never saw the meltdowns that we did, and so the lack of support and understanding I think was the hardest thing”
and “I don’t feel I can leave him for fear of safety because he could hurt himself and
the fear that the person who tried to help could also get hurt.” Distress about their
child’s care and safety as they grew in strength and age was also raised in the context
of low support:

One of my biggest fears is he is going to be a big man… He is going to be tall and
strong. If he is still having these meltdowns when he is a teenager, I’m not going to
be able to control him… And then does that responsibility go onto his brother,
because he will be physically able to hold him? Not a day goes by that you don’t
think about the future and it’s terrifying.

Mental health issues raised as a result of parenting stress were also factors that
contributed to impairment in social and occupational functioning. One mother said
“I’m really not coping at the moment (crying) … I eat and drink food I’m not meant
to… And I try and hide wrappers late at night” and another shared:

I don’t work at the moment because my mental health was so bad… it has taken me a
while to get up. I’ve been in and out of… I’ve had therapy and… Been to rehabs and
tried to get myself healthy and stable… And consistent... And calm for Marcus and
his brother.

Criterion H: The disturbance is not attributable to the physiological effects of a
substance or another medical condition

Criterion H was not spontaneously spoken about by many mothers. When asked
about their self-care strategies, three mothers noted their coping mechanisms after a
“tough day” included the consumption of alcohol in the evenings to reduce their stress levels. One mother described her alcohol intake as “borderline alcoholism” and another acknowledged her history of alcohol and substance use and the need to monitor herself. One mother reported a diagnosed medical condition.

Discussion

We consider the findings from this study to be conservative, as the facilitators of the focus groups neither sought to influence nor orient mothers to speak of trauma-related symptomatology. Rather, mothers attended the focus groups with the knowledge that they would be asked to share challenges they encountered raising a child with ASD. As a result, the information offered by participants about traumatic events and trauma-related symptomatology emerged spontaneously. It is therefore possible that some symptomatology mothers were experiencing were not made overt within the group. Despite this, analysing the data through a trauma lens congruent with DSM-5 PTSD provided rich insight.

The findings were that the majority of traumatic events reported related to three key issues: (1) threat of severe injury or death to the child through their own behaviour; (2) threat of severe injury to the parent from the child; and (3) threat of injury to others. For some mothers these stressors were experienced multiple times per week and involved their child eloping with no road safety knowledge and self-injurious behaviours, which led to physical restraint. Although no longer acknowledged as a diagnostic criterion in the newest edition of the DSM, experiencing fear and helplessness after being exposed to a traumatic event was readily reported by mothers. Experiencing harmful or life-threatening behaviours highlights the need to consider the types of support and intervention that can be offered to these families to
help keep their child safe and to alleviate parent stress (Watson, Hayes, Coons, & Radford-Paz, 2014).

These mothers went on to spontaneously report trauma-related symptomatology, including intrusive symptoms (e.g., marked physiologic reactivity, prolonged distress), negative alterations in cognitions and mood (e.g., persistent and distorted negative beliefs about oneself, persistent trauma-related emotions), alterations in arousal and reactivity (e.g., hypervigilance, problems with sleep) and identified their experiences as causing impairment in their social and occupational functioning. In relation to Criterion C, effortful avoidance of trauma-related stimuli, it is important to consider that the mothers often could not avoid external reminders (e.g., the child themselves, family home), which may trigger other trauma-related symptomatology. They did however appear to detach from negative or trauma-related thoughts and feelings (e.g., “survival mode”). Such self-preservation could explain an additional observation made by facilitators and evidenced in field notes, whereby some mothers appeared to lack emotionality. During moments that could be naturally considered emotional, they actively tried to redirect other mothers who became overtly emotional to a more restrained response.

Most mothers identified the day they received their child’s diagnosis as a recurrent distressing memory. It seemed that mothers experienced ongoing reminders or triggers of this day, which were often linked to caring for their child. Although not recognised as a traumatic event in the DSM-5, this event caused some mothers to spontaneously report trauma-related symptomatology (e.g., intrusive symptoms, alterations in arousal and reactivity, and negative mood and cognition), indicating PTSS. The existence of PTSS in parents resulting from receiving their child’s ASD diagnosis is consistent with Casey et al.’s (2012) findings. The existence of PTSS
challenges the current clinical conceptualisation of traumatic stress involving an individual experiencing an aetiological foundation or precipitant identified in the DSM as traumatic event. Over the past decade there has been an ongoing debate regarding the utility of specifying the type of events that are definitively aetiological. The assumption that exposure to a specific traumatic event(s) is the primary cause of a unique set of stress response symptoms (e.g., PTSD criteria B–G) is problematic, as stressors vary along a number of dimensions including magnitude, complexity, frequency, duration, predictability, and controllability (Weathers & Keane, 2007). Some mothers described experiencing anxiety when talking about their ability to care for their child as he or she ages. Safety was raised, with rhetorical questions of how they would continue to protect their children as they grew in size and strength and restraint was no longer plausible. There was a sense of hope amongst the mothers that their child would outgrow some of their challenging behaviours, which would improve their overall functioning, thereby negating the need for a future decision about care options. Future concerns contributing to parenting stress (e.g., Sharpley, Bitsika, & Efremidis, 1997) and not abandoning hope that significant changes may occur are reported throughout the literature (e.g., Bilgin & Kucuk, 2010). A theme not directly identified in the results section but evident across the data was the tenacity and resilience these mothers demonstrated. Despite exposure to recurrent traumatic events and/or reports of trauma-related symptomatology, as well as a general lack of social and emotional support, they continued to “move heaven and earth for (their) child” and put their child’s wellbeing before their own. Mothers of children with ASD demonstrating resilience in the face of challenges and receiving insufficient support has been documented by other researchers (e.g., Watson et al., 2014). It was apparent that there was a great need for support amongst mothers of
children with ASD. Our findings indicate that such support would, for many, incorporate intervention content and functions informed by evidence-based trauma-focussed programs.

**Limitations and future directions**

Our findings contribute to the growing literature investigating clinical conceptualisations of elevated parenting stress in parents of children with ASD. A modest sample of 12 mothers participated and our attempt to recruit fathers was unsuccessful. Participating mothers thought that the fathers of their children would feel uncomfortable sharing parenting experiences, especially in a group setting. Although the focus group format did stimulate rich conversation amongst the mothers, social influence from some participants reduced the detail of information obtained. For example, some mothers would redirect another mother when she began sharing a difficult experience that caused an outward display of emotion. The mother sharing the experience was typically supported and validated by other group members and the conversation redirected to a more neutral, positive or problem-solving approach. Future research could utilise one-on-one interviews to overcome these identified limitations.

Additionally, five of the twelve mothers reported raising more than one child with ASD. Even though these mothers were asked to speak about the child who was the most challenging to parent, the impact of raising more than one child with ASD on reported trauma symptomatology cannot be discounted. Although the current analysis did not explore this potentially compounding factor, it should be noted that three of the five mothers who met Criterion A for PTSD had one child with ASD. Finally, although a phenomenological approach was adopted as our methodology, the researchers did analyse the data for evidence of spontaneous trauma-related
symptomatology. Measures were taken to avoid influencing participants during data collection (e.g., terms such as “trauma” and “PTSD” were not used in recruitment or during focus groups). Transcripts indicated facilitators did not openly lead participants. However, it is still acknowledged that the preconception of trauma had the potential to influence the focus groups.

**Implications for practice**

Forty percent of mothers reported child-related events that met criteria for a traumatic event in the DSM-5. Some mothers spoke of these events as unrelenting or as recurrent challenges that impacted their wellbeing and capacity to parent. Mothers did not spontaneously use the language “trauma”, instead, depression and anxiety were commonly mentioned, with 50 percent of mothers reporting current use of anti-depressants. Although this form of treatment may be appropriate for mothers who do indeed exhibit depression and/or anxiety, for those reporting symptomatology that may be conceptualised as trauma-related, it is proposed that clinicians use a brief screening measure such as the PTSD Checklist (Weathers et al., 2013). This screening measure may better encapsulate the diverse constellation of symptomatology that some parents present with and would subsequently inform optimal treatment and/or support.

The Australian and international guidelines for the treatment of adults with acute stress disorder and posttraumatic stress disorder (Australian Centre for Posttraumatic Mental Health [ACPMH], 2013) recommend trauma-focussed cognitive behaviour therapy as the best practice intervention. Studies examining the effectiveness of non-trauma focussed interventions (e.g., anxiety management, stress inoculation training) found that these interventions were not as effective as trauma-focussed cognitive behaviour therapy when used in isolation. Pharmacotherapy was nominated as a
second-line treatment (ACPMH, 2013). It was evident in the focus groups that mothers felt anti-depressants improved their overall mood; however, this treatment did not provide them with a repertoire of healthy coping or self-care strategies nor did it appear to alleviate trauma-related symptomatology and resulting psychological and social impacts the mothers reported experiencing on a regular basis. There was also evidence for an association between the severity of child behaviours and mothers’ reports of traumatic events and the presence of trauma-related symptomatology. This highlights the importance of child interventions that aim to reduce problematic behaviours, thereby improving the safety and quality of life for both mothers and the individual with ASD (Seltzer et al., 2010).

**Conclusion**

Mothers of children with ASD do encounter traumatic events defined in the DSM-5 required for the consideration for a trauma-related diagnosis. Traumatic events included children eloping with no road safety knowledge, children engaging in significant self-harming behaviours, and children accidently injuring others (e.g., mother’s broken rib). Regardless of whether a traumatic event was reported, mothers’ discourse still included trauma-related symptomatology, indicating the presence of PTSS. Despite the descriptions of ongoing traumatic events by mothers and the presence of trauma-related symptomatology, what stood out was their resilience. Although some of these mothers acknowledged strained mental health and inadequate self-care strategies, they put their needs on hold and entered into “survival mode” when required to take care of their family.

As professionals, it is our obligation to strive to support the needs of these mothers and their families. Further research into this emerging field is warranted with a larger
sample size, the inclusion of fathers, and the use of psychometrically validated measures of trauma-related psychopathology. This would improve our understanding of the nature of the traumatic stress parents of children with ASD may experience and the degree to which it may contribute to poor mental health outcomes. This information will prove invaluable in developing interventions aimed at supporting the mental health of parents who are experiencing both clinical trauma and PTSS.
References


PTSS in parents of children with ASD


Hamlyn-Wright, S., Draghi-Lorenz, R., & Ellis, J. (2007). Locus of control fails to mediate between stress and anxiety and depression in parents of children with


Chapter 6: Quantitative study examining symptoms of posttraumatic stress in parents of children with ASD

In the previous paper (Stewart et al., in press) 40% of the mothers who participated in our focus groups spontaneously detailed events that would qualify as PTSD traumatic stressors and the presence of trauma symptomatology. They described events that satisfied PTSD Criterion A including: (1) threat of severe injury or death to the child as a result of the child’s behaviour, (2) threat of severe injury to the parent as a result of the child’s behaviour and, (3) threat of severe injury to others as a result of the child’s behaviour. These findings are concerning, as there is no prior research directly exploring PTSD presentations in parents of children with ASD. This suggests a significant gap in the current literature, and likely impacts how mothers of children with ASD who exhibit harmful or life-threatening behaviours are perceived and subsequently supported by health professionals. At the very least, these findings indicate the need for interventions that target child safety and parental stress reduction. The remaining 60% of mothers that did not spontaneous report exposure to traumatic stressors did, however, report symptomatology resulting from challenging child behaviours that were consistent with PTSS. These findings extend upon Casey et al.’s (2012) investigation of PTSS as the variety of events reported by our sample of parents extended well beyond the receipt of their child’s diagnosis (which was the sole focus of the Casey study).

Based on these findings, the following paper (Stewart, McGillivray, Forbes, Mohebbi, & Austin, under review) adopted a quantitative methodology to explore the use of a traumatic stress framework with a robust sample size of parents of children with ASD. A sample consisting of parents raising typically developing children was
also recruited to form a comparison group. It was hypothesised that parents of children with ASD would report higher rates of trauma symptomatology in comparison of parents of typically developing children. Furthermore, it was hypothesised that the frequency of challenging behaviours exhibited by a child with ASD would predict parent reports of trauma symptomatology.
Paper 3

Authorship Statement

1. Details of publication and executive author

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<td>Accepted for review with Journal of Anxiety Disorders</td>
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2. Inclusion of publication in a thesis

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3. HDR thesis author’s declaration

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<th>School/Institute/Division if based at Deakin</th>
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<tr>
<td>Michelle Stewart</td>
<td>School of Psychology</td>
<td>Traumatic stress in parents of children with autism spectrum disorder</td>
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If there are multiple authors, give a full description of HDR thesis author’s contribution to the publication (for example, how much did you contribute to the conception of the project, the design of methodology or experimental protocol, data collection, analysis, drafting the manuscript, revising it critically for important intellectual content, etc.)

Conceptual development of study, design of methodology, ethics application, recruitment, data management and analysis, drafting the manuscript, revisions, principal author.

I declare that the above is an accurate description of my contribution to this paper, and the contributions of other authors are as described below.

Signature and date: 30th July 2016

4. Description of all author contributions

<table>
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<tr>
<th>Name and affiliation of author</th>
<th>Contribution(s) (for example, conception of the project, design of methodology or experimental protocol, data collection, analysis, drafting the manuscript, revising it critically for important intellectual content, etc.)</th>
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<tr>
<td>Michelle Stewart</td>
<td>Conceptual development of study, design of methodology, ethics application, recruitment, data management and analysis, drafting the manuscript, revisions, principal author.</td>
</tr>
<tr>
<td>A/Prof David Austin</td>
<td>Conceptual development of study, design of methodology, review and feedback for manuscript.</td>
</tr>
<tr>
<td>Prof. Jane McElvany</td>
<td>Conceptual development of study, review and feedback for manuscript.</td>
</tr>
<tr>
<td>Prof. David Forbes</td>
<td>Design of methodology, review and feedback for manuscript.</td>
</tr>
<tr>
<td>Dr Mohammadreza Mohebbi</td>
<td>Data analysis, review and feedback for manuscript.</td>
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5. Author Declarations

I agree to be named as one of the authors of this work, and confirm:
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ii. that there are no other authors according to these criteria,
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<td>30th July 2016</td>
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<td>A/Prof David Austin</td>
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<td>3rd August 2016</td>
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<td>Prof Jane McGillivray</td>
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6. Other contributor declarations

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<td>20th July 2015</td>
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If the publication is to be included as part of an HDR thesis, a copy of this form must be included in the thesis with the publication.
Symptoms of posttraumatic stress in parents of children with autism spectrum disorder

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Abstract
This study investigated the validity of conceptualising elevated stress levels in parents of children with autism spectrum disorder (ASD) within a traumatic stress framework. The rationale for this framework was based upon the notion that parents may be exposed to threatened or actual serious injury to their child or another as a result of parenting challenging and potentially dangerous behaviours. The Life Events Checklist for DSM-5, Developmental Behaviour Checklist (Parent) and PTSD Checklist for DSM-5 were administered to 256 parents. Results showed that being a parent of a child with ASD accounted for 28.6% of the variance in trauma scores. Additionally, frequency of challenging child behaviours explained 29.5% of variance in trauma scores for parents of children with ASD. Findings support the need to extend our understanding of trauma responses amongst parents of children with ASD, as the clinical manifestation of PTSD in this cohort would have negative implications for both the parents and their children.
1. Introduction

Autism Spectrum Disorder (ASD) affects approximately 1.47% of the world’s population (Centre for Disease Control and Prevention, 2014) and is defined by deficits in socio-communicative behaviours, and the presence of stereotypical behaviours and a restricted range of interests (American Psychiatric Association, 2013). The psychopathology of ASD in children exposes parents to unique challenges. For example, children with ASD can be difficult to understand due to atypical interpersonal responsiveness (e.g. outbursts of physical and verbal behaviours or lack of engagement/language) and unusual patterns of communication (e.g., repetitive or illogical phrasing) (Busch, 2009; Mount & Dillon, 2014).

Some challenges associated with parenting a child with ASD have implications for the functioning of their parents and the wider family unit. The existing literature clearly demonstrates that parents of children with ASD report higher levels of stress than parents of children who are typically developing and, indeed, parents of children with other serious clinical conditions (Bitsika & Sharpley, 2004; Hayes & Watson, 2013). Elevated stress and other mental health difficulties including anxiety and depression are thought to reduce parental capacity to manage the challenges of raising a child with ASD, including their ability to implement strategies and programs that may be of benefit to their child (Osborne, McHugh, Saunders, & Reed, 2007). Thus, supporting children with ASD and their families’ demands, not only involves direct intervention work with the child, but also understanding and intervening in parental mental health.

A considerable body of research has identified contributing factors to parental stress, including unmet service needs (Taylor & Seltzer, 2010), low levels of perceived family support (Bromley, Hare, Davison, & Emerson, 2004), and low self-
confidence in their own ability to manage their child’s daily behavioural difficulties (Bitsika & Sharpley, 2004). Although findings are inconsistent across clinical and community samples, ASD symptom severity (Benson, 2006; Hall & Graff, 2011) and externalising behaviours in the child with ASD (Brei, Schwarz, & Klein-Tasman, 2015; Lecavalier, Leone, & Wiltz, 2006; Manning, Wainwright, & Bennett, 2011) are commonly identified as child-related factors which contribute to elevated levels of parent stress. Elopement, aggression, and self-injurious behaviours seen in some children with ASD can represent a genuine risk of danger to the child (or other) as a result of misadventure. Therefore, it is proposed that some parents experience fears for the ongoing safety of their child and/or others in contact with their child. The notion of parents being exposed to events characterised by threatened or actual serious injury and/or death warrants consideration for traumatic stress, as defined in the Diagnostic and Statistical Manual of Mental Health Disorders (5th edition) (DSM-5; American Psychiatric Association, 2013) for trauma and stressor-related disorders.

There is a dearth of research investigating the validity of conceptualising parent stress as traumatic stress. 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 is used when an event does not satisfy Criterion A (traumatic stressor) for a DSM-5 posttraumatic stress disorder (PTSD), but the individual still exhibits PTSD symptomatology. After surveying 265 parents (245 mothers), Casey et al. reported 20% of parents endorsed moderate to high levels of PTSS, including PTSD diagnostic criteria of intrusion, avoidance, and hyperarousal.
The existence of PTSD symptomatology in parents of children with ASD has also been reported in studies utilising physiological measures including saliva cortisol levels. When compared to control groups, Seltzer et al. (2010) reported lower levels of cortisol in mothers of adolescents and adults with ASD and Foody et al. (2014) found lower cortisol levels in mother-father dyads of younger children with ASD. Seltzer et al. (2010) also reported that mother’s cortisol levels remained low even after controlling for maternal age, prescription medication usage, and saliva collection time. Seltzer et al. (2010) identified the influence of specific child behaviours on cortisol levels, including self-injurious behaviour, repetitive behaviour, and uncooperative behaviour (Seltzer et al., 2010). 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, Ehlert, & Hellhammer, 2000; Miller, Chen, & Zhou, 2002; Yehuda, Boisoneau, & Giller, 1995). Thus there appears to be a subpopulation of parents of children with ASD who exhibit cortisol profiles comparable to a clinical population of individuals exposed to a traumatic stressor and/or who have a PTSD diagnosis. These parents, therefore, may be at risk of compromised mental and physical health, including decreased immunity, fatigue-like symptoms, and increased vulnerability to stress-related diseases including hypertension, stroke, and coronary heart disease (Sapolsky, 2004). Additionally, their efficacy as caregivers may be compromised (Cabizuca, Marques-Portella, Mendlowicz, Coutinho, & Figueira, 2009).

The purpose of the current investigation was to explore stress in parents of children with ASD using DSM-5 PTSD diagnostic criteria, and to investigate whether child-related behaviour difficulties predicted PTSD symptomatology. It was hypothesised that (1) parents of children with ASD would endorse higher levels of...
PTSS in parents of children with ASD

PTSD symptomatology in comparison to parents of typically developing children and (2) the frequency of a child’s challenging behaviours would predict PTSD symptomatology in parents of children with ASD.

2. Materials and methods

2.1 Participants and Procedure

Participants were recruited from throughout Australia using social media, ASD forums, ASD support groups, and ASD-relevant non-government organisations. In total, 256 parents (248 mothers) completed the online questionnaire. There were two subgroups: parents of children with ASD and parents of typically developing (TD) children.

Of the 226 parents of children with ASD (219 mothers), the mean age was 42.2 years ($sd = 6.3$). The sample of children they reported on comprised 80% males, with an overall mean age of 13.6 years ($sd = 3.8$) and mean age at diagnosis of 5.1 years ($sd = 3.0$). 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. Paediatricians diagnosed 53% of the children, psychologists 28%, psychiatrists 10%, and GP or other 9%. Diagnoses included autism (39%), Asperger’s syndrome (34%), high functioning autism (18%), and PDD-NOS (9%). Common mental and physical health comorbidities 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 (4.9%).

Of the 30 parents of TD children (29 mothers), the mean age was 39.9 years ($sd = 5.0$). The sample of children reported on comprised 47% males, with an overall mean age of 10.0 years ($sd = 3.7$). None of the TD children were reported to have a current
diagnosis of a mental or physical health condition. Of the total parent sample, 73% identified themselves as being in a relationship and 27% were currently without a partner.

Approval to conduct the study was granted by the Deakin University Human Research Ethics Committee. Before commencing the questionnaire, parents were asked to identify whether they were reporting about a child with ASD or a TD child. If parents had more than one child with an ASD diagnosis ($n = 10$) 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 on to complete the questionnaire.

2.2 Measures

2.2.1 The Life Events Checklist for the DSM-5 (LEC-5) (Weathers et al., 2013a)

The LEC-5 was used to screen for parent’s exposure to traumatic stressors throughout their lifetime. There are 16 events in total and one additional item assessing for any extraordinarily stressful event. The LEC 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 et al., 2004).

2.2.2 The PTSD Checklist for the DSM-5 (PCL-5) (Weathers et al., 2013b)

The PCL-5 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, “keeping in mind the experience of parenting your child with ASD” was added to direct their focus 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 endorsed items (‘2=moderately’ or above) to fulfil DSM-5 PTSD diagnostic criteria. The PCL-5 demonstrates good internal consistency (Cronbach’s alpha = .95) (Armour et al., 2015).

2.2.3 The Developmental Behaviour Checklist (Parent version) (DBC-P) (Einfeld & Tonge, 2002)

The DBC-P was used to assess for behavioural and emotional disturbances in children. Parents are asked to consider their child’s behaviours over the past six months when answering a 96-item checklist. A 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). 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, self-absorbed, communication disturbance, anxiety, and social relating. The TBPS has been demonstrated to have good reliability (ICC = .8, 99% CI [0.59, 0.90]) and validity (Einfeld & Tonge, 1995). The subscales also possess strong internal consistency (Cronbach’s alpha range= .71-.91) and reliability (ICC range = (99% CI [0.66, 0.88]).

3. Data Analysis and Results

3.1 Posttraumatic stress amongst parents

Of the 226 parents of children with ASD, 53 (23.45%) met the clinical cut off score (>38) on the PCL-5 required for consideration for a provisional PTSD diagnosis. A more stringent approach used with the PCL-5 is for respondents to meet the clinical cut off score and endorse the required number of DSM-5 PTSD criteria
for a diagnosis. Of the 53 parents who met the PCL-5 clinical cut off, 42 (79.2%) endorsed the required number of criteria for consideration of a provisional PTSD diagnosis. Of the 30 parents of typically developing children, none met the clinical cut off score or endorsed the required number of PTSD criteria required to consider a diagnosis.

Tri-variate ANCOVA analyses were conducted with the Group variable (parent of ASD child, parent of TD child) and each LEC-5 event. Only direct experiences of a LEC-5 event (i.e., ‘happened to me’) were included (see Table 1). Results indicated in addition to Group factor, direct experiences with eight events from the LEC-5 were significant ($p < .1$) in explaining variance in PCL-5 scores.
Table 1

Univariate ANCOVA of PCL-5 Scores When Controlling for LEC-5 Items

<table>
<thead>
<tr>
<th>Variable</th>
<th>B [95% CI]</th>
<th>F</th>
<th>$\eta^2_p$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group</td>
<td>19.10 [13.08, 25.12]</td>
<td>39.07***</td>
<td>0.13</td>
</tr>
<tr>
<td>Natural disaster</td>
<td>4.33 [-0.11, 8.78]</td>
<td>3.68</td>
<td>0.01</td>
</tr>
<tr>
<td>Group</td>
<td>17.54 [11.66, 23.42]</td>
<td>34.55***</td>
<td>0.12</td>
</tr>
<tr>
<td>Physical assault</td>
<td>8.97 [5.04, 12.90]</td>
<td>20.20***</td>
<td>0.07</td>
</tr>
<tr>
<td>Group</td>
<td>17.97 [12.18, 23.77]</td>
<td>37.33***</td>
<td>0.13</td>
</tr>
<tr>
<td>Assault with a weapon</td>
<td>15.88 [9.71, 22.05]</td>
<td>25.71***</td>
<td>0.09</td>
</tr>
<tr>
<td>Group</td>
<td>18.89 [12.06, 24.71]</td>
<td>40.81***</td>
<td>0.14</td>
</tr>
<tr>
<td>Life threatening injury or injury</td>
<td>12.07 [6.91, 17.23]</td>
<td>21.24***</td>
<td>0.08</td>
</tr>
<tr>
<td>Group</td>
<td>18.96 [12.97, 24.97]</td>
<td>38.80***</td>
<td>0.13</td>
</tr>
<tr>
<td>Serious injury, harm, death you caused someone</td>
<td>26.87 [14.77, 48.37]</td>
<td>7.75*</td>
<td>0.02</td>
</tr>
<tr>
<td>Group</td>
<td>18.92 [12.92, 24.92]</td>
<td>38.62***</td>
<td>0.13</td>
</tr>
<tr>
<td>Fire or explosion</td>
<td>7.93 [1.44, 14.43]</td>
<td>5.78*</td>
<td>0.02</td>
</tr>
<tr>
<td>Group</td>
<td>17.30 [11.30, 23.31]</td>
<td>32.22***</td>
<td>0.11</td>
</tr>
<tr>
<td>Sexual assault</td>
<td>7.80 [3.51, 11.90]</td>
<td>12.80***</td>
<td>0.05</td>
</tr>
<tr>
<td>Group</td>
<td>17.17 [10.99, 23.34]</td>
<td>29.91***</td>
<td>0.11</td>
</tr>
<tr>
<td>Any other very stressful experience</td>
<td>5.23 [1.24, 9.49]</td>
<td>6.57*</td>
<td>0.02</td>
</tr>
<tr>
<td>Group</td>
<td>19.07 [13.00, 25.14]</td>
<td>38.28***</td>
<td>0.13</td>
</tr>
<tr>
<td>Exposure to toxic substance</td>
<td>3.17 [-7.43, 13.88]</td>
<td>0.35</td>
<td>0.00</td>
</tr>
<tr>
<td>Group</td>
<td>19.14 [13.09, 25.20]</td>
<td>38.76***</td>
<td>0.13</td>
</tr>
<tr>
<td>Serious accident at work or home</td>
<td>3.5 [-4.3, 9.6]</td>
<td>0.56</td>
<td>0.00</td>
</tr>
<tr>
<td>Group</td>
<td>18.68 [12.62, 24.76]</td>
<td>36.78***</td>
<td>0.13</td>
</tr>
<tr>
<td>Other unwanted sexual experience</td>
<td>3.06 [-0.91, 7.02]</td>
<td>2.31</td>
<td>0.01</td>
</tr>
<tr>
<td>Combat or exposure to war zone</td>
<td>-6.09 [-37.34, 25.15]</td>
<td>0.15</td>
<td>0.00</td>
</tr>
<tr>
<td>Group</td>
<td>19.46 [2.68, 28.53]</td>
<td>40.31***</td>
<td>0.14</td>
</tr>
<tr>
<td>Captivity</td>
<td>12.97 [-2.08, 28.95]</td>
<td>2.66</td>
<td>0.01</td>
</tr>
<tr>
<td>Group</td>
<td>19.23 [13.13, 25.31]</td>
<td>38.86***</td>
<td>0.13</td>
</tr>
<tr>
<td>Severe human suffering</td>
<td>1.36 [-16.80, 19.52]</td>
<td>0.02</td>
<td>0.00</td>
</tr>
<tr>
<td>Sudden violent death</td>
<td>6.52 [-4.03, 17.07]</td>
<td>1.48</td>
<td>0.01</td>
</tr>
<tr>
<td>Group</td>
<td>18.92 [12.87, 24.98]</td>
<td>37.88***</td>
<td>0.13</td>
</tr>
<tr>
<td>Sudden accidental death</td>
<td>6.98 [-3.58, 17.56]</td>
<td>1.70</td>
<td>0.01</td>
</tr>
<tr>
<td>Group</td>
<td>19.08 [12.98, 25.19]</td>
<td>37.88***</td>
<td>0.13</td>
</tr>
<tr>
<td>Transportation accident</td>
<td>0.62 [-3.32, 4.55]</td>
<td>0.10</td>
<td>.000</td>
</tr>
</tbody>
</table>

Note: N = 256. Reference (baseline) group = parents of children with ASD.

*p < 0.05. **p < 0.01. ***p < 0.001.
Multivariate ANCOVA with all covariates significant at $p < .1$ level was then conducted. A backward variable selection technique was then implemented, and covariates with highest p-value were removed one at the time until all factors were significant at $p < .05$ level (see Table 2). In the multivariate analysis, only five of these events remained significant. The estimated effect for fire or explosion decreased from 7.9 to 2.5 in the multivariate analysis, indicating its power decreased as a result of the inclusion of the over variables. This was also the case for sexual assault (7.8 to 2.2), and any other stressful event/experience (2.6 to 1.5). Group remained significant in both the univariate and multivariate analyses, demonstrating a large effect size. Partial eta squared is reported as a measure of effect size. This measure provides an estimate of the proportion of the total variance accounted for by the factor under consideration, in which small, medium, and large effects were operationalised as .01, .06, and .14, respectively (Richardson, 2011). Group accounted for 28.6% of the variance in PCL-5 scores. The mean difference for scores on the PCL-5 indicated parents of children with ASD reported an estimated a mean of 16.9 points (95% CI [11.3, 22.4]; $p < .001$) higher than parents of TD children, which was accompanied by a large effect size of 0.13.
3.2 Challenging behaviours as predictors of trauma symptomatology

The mean Total Problem Behaviour Score (TBPS) on the DBC-P for parents of children with ASD was 74.96 (sd = 29.77). The total number of parents of children with ASD who had a TBPS in excess of 46, indicative of clinical levels of emotional and behavioural disturbances, was 14.6%. To explore the association between the frequencies of a child’s challenging behaviours and trauma symptomatology a regression analysis was performed. A similar backward variable selection strategy was implemented. First, demographic variables and each DBC-P behaviour domain were individually regressed against the dependent variable (PCL-5) for the ASD parent group. In the bivariate regressions, all DBC-P behaviour domains were significant ($p < .001$) (see Table 3).
In the multivariate regression model only three DBC-P domains remained significant at $p<.01$ (see Table 3). DBC-P domains *disruptive-antisocial, self-absorbed*, and *anxiety* were significant covariates, accounting for 29.5% of the variance in parent’s PCL-5 scores ($F=32.4, p<.001$), each demonstrating a small to medium effect size (0.04 to 0.06) (see Table 4). Importantly, even when controlling for the five LEC-5 items that were significant in the multivariate ANCOVA (table 2), these three DBC-P domains remained significant predictors of variance in parent’s PCL-5 scores (disruptive-antisocial $p < .05$, $\eta_p^2 = 0.03$; self-absorbed $p < .01$, $\eta_p^2 = 0.04$; anxiety $p < .01$, $\eta_p^2 = 0.03$).

The more frequently endorsed disruptive-antisocial items included: ‘deliberately runs away’, ‘kicks, hits others’ and ‘throws or breaks objects.’ Items
for self-absorbed included: ‘chews or mouths objects, or body parts’, ‘hits self or bites self’, and ‘poor Sense of danger’. Items for anxiety included: ‘fears particular situations’, ‘fussy eater or has food fads’, and ‘upset or distressed over small changes in routine or environment.’ 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. In addition to the above frequently endorsed items on the DBC-P, these parents also endorsed ‘talks of suicide’ (11% often true, 31% sometimes true), ‘screams a lot’ (26.19% often true, 28.57% sometimes true), and ‘bangs head’ (14.29% often true, 42.86% sometimes true).

<table>
<thead>
<tr>
<th>Variable</th>
<th>B [95% CI]</th>
<th>SE B</th>
<th>F</th>
<th>$\eta^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disruptive-antisocial</td>
<td>0.34 [0.12, 0.56]</td>
<td>0.22</td>
<td>9.16**</td>
<td>0.04</td>
</tr>
<tr>
<td>Self-absorbed</td>
<td>0.40 [0.18, 0.62]</td>
<td>0.26</td>
<td>13.17*</td>
<td>0.06</td>
</tr>
<tr>
<td>Anxiety</td>
<td>0.84 [0.30, 1.37]</td>
<td>0.19</td>
<td>9.58**</td>
<td>0.04</td>
</tr>
</tbody>
</table>

Note: N=226.
PCL-5 = PTSD Checklist for DSM-5. DBC-P = Developmental Behaviour Checklist (parent version)
* $p < 0.01$. ** $p < 0.001$

4. Discussion

After accounting for exposure to DSM-5 PTSD traumatic stressors required for the recognised development of PTSD, 28.6% of the variance in self-reported trauma symptomatology on the PCL-5 was explained by being a parent of a child with ASD. After adopting more stringent criteria when interpreting results of the PCL-5, a substantial minority of parents of children with ASD (18.6%) reported trauma symptomatology required for consideration of 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. Therefore, our hypothesis that parents of children with ASD would endorse higher rates of trauma symptomatology in comparison to parents of typically developing children was supported.

Similar to Casey et al. (2012) who reported PTSS in 20% of parents in the context of receiving their child’s ASD diagnosis, 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. The finding that 18.6% of parents of children exhibited a psychological profile consistent with someone experiencing PTSD is concerning given the general Australian population PTSD prevalence rate of 6.4% (Australian Bureau of Statistics, 2007). Additionally, these results expand on those of Casey et al by demonstrating that parents continue to experience PTSS well beyond receiving their child’s ASD diagnosis.

The multivariate ANCOVA also demonstrated that exposure to five of the sixteen LEC-5 traumatic stressors were also significant contributors to the variance in PCL-5 scores. These stressors were natural disaster, physical assault, assault with a weapon, life threatening illness or injury, and serious injury, harm of death you caused someone. With the exception of natural disaster, a parent of a child with ASD could encounter these traumatic stressors as part of their parenting experience given the challenging behaviours endorsed. This hypothesis requires empirical investigation, as our understanding of events experienced that caused parents to endorse these traumatic stressors is limited by the nature of data collection.
Domains of challenging child behaviours that were predictive of higher scores on the PCL-5 for parents of children with ASD included disruptive-antisocial, self-absorbed, and anxiety. This result is consistent with previous studies that have demonstrated challenging child behaviours contribute to increased parent stress levels (e.g., Brei et al., 2015; Lecavalier et al., 2006). Of the 42 parents of children with ASD who met stringent criteria for the consideration of a provisional PTSD diagnosis, each parent reported emotional and behaviour disturbances that were in the clinical range. Furthermore, these parents also reported behaviours that could qualify as a Criterion A traumatic stressor required for a DSM-5 PTSD diagnosis (e.g., bangs his/her head, talks of suicide, kicks or hits others, poor sense of danger, hits self or bites self, and deliberately runs away). Importantly, exposure to behaviours within the three DBC-P domains remained significant predictors of PCL-5 scores despite controlling for the five LEC-5 items. Therefore, although some variance in PCL-5 scores may reflect prior exposure to traumatic stressors, exposure to challenging child behaviours accounted for close to one third of variance in PCL-5 scores (29.5%).

Communication disturbances and social relating were nonsignificant in the multivariate regression model. Individual items on the DBC-P for these two domains predominately relate to pronouns, prosody, obsessions and preoccupations, and dislike of physical touch. Unlike the other three domains, these aforementioned behaviours are not easily interpretable within a traumatic stress framework. Instead, they are hypothesised to be potential precipitants to challenging behaviour. For example, transitioning a child away from an obsession may result in both an emotional and behavioural reaction that could result in parents endorsing behaviours on other DBC-P domains.
4.1 Clinical Implications

Health professionals need to be aware that some parents of children with ASD may be exposed to events related to their child’s behaviours that lead to the experience of traumatic stress. Although further research in this emerging field is required, utilising brief trauma screens like the PCL-5 may assist health professionals in determining whether parents have experienced a traumatic stressor defined by criterion A for PTSD in the DSM-5. If a traumatic stressor was identified, clinicians should thoroughly assess for PTSD. The outcome of such an assessment would indicate whether trauma-informed care was indicated as best practice.

4.2 Study Limitations and future directions

One limitation is the reliance on self-report given the measures were administered online, which also limits findings to symptomatology as opposed to psychopathology. Nevertheless, the methodology employed served as an efficient method of obtaining a robust sample size and ensuring parents’ anonymity. Mothers were also over-represented within the sample (96.9%), and, therefore, the results may not be generalisable to fathers.

The current study adopted a cross sectional design and it is recommended that future exploration of causal pathways involve longitudinal analysis. Future research would also benefit from adopting gold standard clinical interviews (e.g., Clinician Administered PTSD Scale for the DSM-5) to gain a more definitive clinical understanding of the trauma profiles that are evidenced in this study’s sample. The inclusion of fathers in future research is also important, as males and females often exhibit different trauma psychopathology. Lastly, the current study has identified challenging behaviours accounting for 29.5% of the variance in parent’s trauma scores on the PCL-5. There remains another 70.5% of unexplained variance which
warrants additional research to gain a greater understanding of the factors that contribute to an increased risk of trauma symptomatology in parents of children with ASD.

5. Conclusion

Results from the current study provide evidence of PTSS in a subpopulation of parents of children with ASD who range from four to eighteen years of age. This subpopulation of parents endorsed clinical levels of emotional and behavioural disturbances in their child. The results highlighted the dangerous nature of some of the behaviours children display, as they were associated with risk of actual or threatened serious injury, or in extreme cases, death. This suggests that health professionals would be wise to remain cognisant of the fact that parents of children with ASD may be exposed to traumatic stressors as a result of child behaviours, and in response, exhibit symptomatology that could be conceptualised within a traumatic stress framework.
References


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(2nd. ed.). Clayton, Melbourne: Monash University Centre for Developmental Psychiatry and Psychology.


Chapter 7: Discussion

7.1 General discussion

Although research has consistently revealed that parents of children with ASD experience significantly elevated levels of stress, there is no consistent, or agreed upon, definition of the form of stress that the parents are experiencing. Definitions of stress in the current literature include stress (e.g., Abbeduto et al., 2004), parenting stress (e.g., McStay et al., 2014), and psychological distress (e.g., Bromley et al., 2004). The lack of a consistent definition is problematic when seeking to inform a greater understanding at an aggregate level.

A review of the ASD literature that has examined factors that contribute to elevated parental stress showed that challenging child behaviours have been frequently identified. Behaviours range in intensity, with the more severe behaviours being self-injurious behaviours, physical aggression, suicidal behaviour, and elopement (responsible for the highest standardised mortality rate in children with ASD; Shavelle et al., 2001). Although these behaviours are challenging, they are also potentially dangerous for both the child and parent. These behaviours may result in exposure to actual or threatened serious injury, and in some cases, actual or threatened death through misadventure. The question that this thesis was concerned with was, therefore, whether some parents of children with ASD experience traumatic stress (as defined by the PTSD diagnostic framework in the DSM-5). This question formed the central focus for this thesis, and an investigation of the validity of conceptualising some parenting experiences and resulting mental health symptomatology within a traumatic stress framework was conducted.

The first paper presented in this thesis (Parenting a child with an autism spectrum disorder: a review of parent mental health and its relationship to a trauma-
PTSS in parents of children with ASD

Chapter 4) reviewed the factors that had a pervasive impact upon the mental health of parents of children with ASD, the diagnoses that were most prevalent amongst this population, and prior studies adopting a traumatic stress framework.

Challenging and dangerous child behaviours, as well as social consequences (e.g., scrutiny by the public, isolation, child being socially devalued), were identified as factors most commonly associated with a negative impact on parent mental health. Mood and anxiety diagnoses were commonly reported, however, parent stress appeared to be the most researched construct in relation to parent mental health. This first paper highlighted the dearth of research investigating the validity of a traumatic stress framework in trying to understand the mental health sequelae of parents of children with ASD, with only one psychological and two physiological studies identified. Casey et al. (2012) reported evidence of posttraumatic stress symptoms manifesting in parents of children who had recently received their child’s ASD diagnosis. Although it is not known whether or not parents had been exposed to a Criterion A traumatic stressor, 20% reported moderate to high level of posttraumatic stress symptoms, including intrusion or re-experiencing, avoidance, and hyperarousal (DSM-IV-TR). This finding challenges the assumption that exposure to a specific aetiological event, as defined by the DSM-5, represents an exclusive casual pathway to the subsequent development of trauma symptomatology.

The two physiological studies reviewed in the paper provided empirical support for the notion of a trauma-based response at a biological level (Foody et al., 2014; Seltzer et al., 2010). Cortisol profiles amongst parents of children with ASD were comparable to individuals who had experienced Criterion A traumatic stressors as part of the PTSD diagnostic framework (i.e., combat soldiers). The review
concluded by positing that some parents may not necessarily exhibit symptomatology reflective of a discrete mood and/or anxiety disorder. If a PTSD Criterion A traumatic stressor was present, an interpretation of symptomatology from a trauma-based perspective may be warranted.

The second paper presented in this thesis (Through a trauma-based lens: A qualitative analysis of the experience of parenting a child with an autism spectrum disorder; Chapter 5) utilised qualitative methodology to explore the face validity of adopting a traumatic stress framework with mothers of children with ASD. This approach allowed for a detailed and personal account of parents’ perspectives of the impact of raising a child with significantly challenging behaviours. In a sample of twelve mothers, five spontaneously reported Criterion A traumatic stressors and trauma symptomatology. Child behaviours that were spontaneously reported that qualified as a Criterion A traumatic stressor included physical aggression towards objects and people, elopement, and self-injurious behaviours. Mothers reported using physical restraint in these situations in an effort to decrease the likelihood of a serious injury occurring to their child or another person.

These five mothers went on to describe experiencing symptomatology that could be accounted for within a traumatic stress framework (i.e., intrusion, avoidance, negative alterations in cognition and mood, marked alteration in arousal and reactivity). It is perhaps unsurprising that mothers referred to their symptomatology as depression and/or anxiety, with six mothers (50%) currently taking prescription anti-depressants. Although the mothers believed the anti-depressants helped to improve their overall mood, this treatment in isolation did not appear to alleviate their trauma symptoms. The experiences reported by these
mothers supported the validity of using a traumatic stress framework amongst this population.

The remaining seven (60%) mothers spoke of trauma symptomatology arising from non-traumatic stressors, which supported Casey et al.’s (2012) finding of posttraumatic stress symptoms (i.e., presence of trauma symptomatology in lieu of a Criterion A traumatic stressor). These mothers perceived receiving their child’s diagnosis, their child continuously screaming, faecal smearing, their child’s lack of social communication, and/or societal judgement as the most distressing aspects of raising a child with ASD.

The third paper presented in this thesis (Symptoms of posttraumatic stress in parents of children with ASD; Chapter 6) utilised quantitative methodology to explore parent symptoms from within a traumatic stress framework amongst a robust sample of parents. Of the 226 parents of children with ASD who participated, 53 (23.4%) met the clinical cut off score on the PTSD Checklist for DSM-5 required for consideration of a clinical diagnosis of PTSD. Furthermore, of these 53 parents, 42 endorsed the required number of DSM-5 PTSD criteria required for a diagnosis (following establishment of a Criterion A traumatic stressor). By contrast, no parents of typically developing children met the clinical cut off or required DSM-5 PTSD criteria.

Understanding the factors that contribute to higher levels of reported trauma symptomatology amongst parents of children with ASD is important. When controlling for prior exposure to Criterion A traumatic stressors using the Life Events Checklist for the DSM-5, 28.6% of the variance in trauma scores on the PTSD Checklist was accounted for by being a parent of a child with ASD. In this study, challenging child behaviours were also investigated, as it was hypothesised that
parents of children with ASD who reported more frequent challenging behaviours would report higher levels of trauma symptomatology. Results demonstrated that three behavioural domains, measured by the Developmental Behaviour Checklist (parent version), explained 29.5% of the variance in parent trauma scores on the PTSD Checklist. These domains were disruptive-antisocial, self-absorbed, and anxiety. Information gathered via the Developmental Behaviour Checklist revealed that parents who reported higher levels of trauma symptomatology also tended to report child behaviours that could qualify as Criterion A traumatic stressors (e.g., ‘bangs his/her head’, ‘poor sense of danger’, ‘deliberately runs away’). That is, these behaviours are not only challenging to witness/parent, but appear to be associated with a genuine risk of danger and realistic parental fears for the ongoing safety of their child through adverse/misadventure events.

The finding that challenging child behaviours that occurred over the past six months explained almost a third of the variance in parent trauma scores on the PTSD Checklist is consistent with the work of Seltzer et al. (2010). Seltzer et al. reported a positive association between challenging child behaviours and unusual cortisol profiles in parents. Seltzer and colleagues also highlighted the importance of considering the interaction between a parent’s daily stress and chronic stress resulting from exposure to challenging child behaviours.

The findings of this study also extended upon the work of Casey et al. (2012), as parents were found to report posttraumatic stress symptoms well beyond the period immediately following the receipt of the child’s diagnosis. Although challenging child behaviours accounted for almost one third of the variance in parent’s trauma scores on the PTSD Checklist, further research is warranted in order
to identify and further understand other factors that may contribute to posttraumatic stress symptoms in this population.

### 7.1.2 Limitations

A limitation of the results presented in this thesis is the lack of gold standard clinical assessment. Ideally, the parents in our studies that self-reported symptoms and experiences consistent with a clinical diagnosis of PTSD would have been followed-up with formal clinical interview. Although this further work was beyond the scope of this thesis, this work is indeed planned in the future. For the preliminary work presented in this thesis, the construct of PTSD amongst parents of children with ASD was explored qualitatively (via the use of focus groups) and quantitatively (via self-report online questionnaire), which do not enable firm conclusions to be drawn regarding DSM-5 PTSD diagnoses. Although mothers in the focus groups spontaneously reported Criterion A traumatic stressors and trauma symptomatology, the purpose of this study was not to diagnose parents with PTSD but, rather, to explore the face validity of a traumatic stress framework (*Through a trauma-based lens: A qualitative analysis of the experience of parenting a child with an autism spectrum disorder;* Chapter 5). The online questionnaire relied on parent self-report. Interestingly, parents who reported trauma symptomatology required for the consideration of a provisional PTSD diagnosis also tended to report child behaviours that may potentially be Criterion A traumatic stressors (such as self-injurious behaviours and elopement) (*Symptoms of posttraumatic stress in parents of children with autism;* Chapter 6).

It was not feasible to conduct formal clinical assessments to validate the accuracy of parent reports of their children’s ASD diagnoses. Nevertheless, a
conservative approach was adopted whereby parents were required to provide their child’s formal diagnosis and identify health professional who provided the diagnosis. Consequently, any errors in diagnosis (or parental report of diagnosis) that did occur would be unlikely to have been prevalent enough to substantially influence the results of the studies.

A gender disparity in participating parents was also evidenced across the empirical studies presented in this thesis. Fathers were not successfully recruited to take part in the focus groups and they comprised just 3% of participants in the quantitative study \(^n=7\). Although fathers were specifically targeted for recruitment in both the qualitative and quantitative studies (due to an obvious lack of males in most studies that have recruited parents of children with ASD), the resulting sample comprising predominately mothers was disappointing, albeit not entirely unexpected. Results presented in this thesis therefore cannot be assumed to generalise to fathers.

### 7.1.3 Clinical implications

Significant (and sometimes exclusive) emphasis is placed on the provision of interventions aimed at supporting children following their ASD diagnosis, with parent mental health being a secondary consideration. A parent’s desire to support their child’s development is understandable, and thus it becomes the responsibility of health professionals who are involved with the parents to consider whether the more common diagnoses seen in this population (depression and/or anxiety) are the most valid and useful clinical conceptualisations or whether a traumatic stress framework may be more appropriate.

The findings of this thesis suggest that health professionals should be mindful of parents reporting events that are consistent with a Criterion A traumatic stressor,
and to consider the use of a brief trauma screen (e.g., PCL-5; Weathers et al., 2013) to determine whether a more in-depth assessment is warranted. The importance of recognising exposure to a Criterion A traumatic stressor is considered critical because anxiety and depression are the two primary factors which comprise the PTSD construct. Anxiety and mood disorders are also recognised as possible co-morbid diagnoses with PTSD, further highlighting the need for gold standard assessment when indicated.

Challenging and dangerous child behaviours were demonstrated to explain almost a third of the variance in parent trauma scores on the PTSD Checklist and, therefore, health professionals should also be cognisant of the child behaviours parents are encountering as part of a comprehensive assessment of exposure to Criterion A traumatic stressors. Seltzer et al. (2010) suggested an examination of a parent’s immediate response to their child’s problematic behaviour may assist in identifying PTSD, as they would be more likely to be highly sensitised to arousing stimuli associated with a trauma experience. This response from the parent, along with intrusive thoughts, numbing, emotional distancing, fatigue, and attentional problems are proposed to contribute to their abnormal physiological state associated with chronic stress (Fries, Hesse, Hellhammer, & Hellhammer, 2005).

The adverse impact of challenging child behaviours also indicates the importance of interventions aimed at reducing the frequency of challenging child behaviours. Nevertheless, this conclusion should not be implemented in isolation, as prior research has demonstrated that interventions that support parents in reducing their child’s challenging behaviours do not necessarily reduce parent stress. A more holistic approach to parent mental health may therefore be required.
Ruiz-Robledillo and colleagues (2014) found that a multimodal approach to care, which focused on the child diagnosed with ASD as well as the parent, improved cortisol regulation in parents. The intervention involved access to parent support groups, legal support, cognitive behavioural therapy to improve coping strategies, and psychological and occupational therapy for their child. The program also included respite care one day per week and fifteen days in summer. Although the specifics of the psychological care parents received were not explicitly stated, these findings emphasise the importance of providing intervention specifically related to parent mental health.

Adopting a multimodal approach with parents who are diagnosed with PTSD would also likely be highly beneficial. The psychological intervention provided to parents should be informed by best practice clinical intervention for trauma. The Australian Guidelines for the Treatment of Adults with Acute Stress Disorder and PTSD indicates that trauma-focused cognitive behaviour therapy (TFCBT) is one of the most effective interventions (ACPMH, 2013). These guidelines also acknowledge the benefits of adopting a stepped care approach, which acknowledges that not all individuals who experience a Criterion A traumatic stressor will develop a diagnosable disorder, instead presenting with subthreshold PTSD symptoms. Within a stepped care approach the aim would be to provide practical and emotional support, and to encourage parents to utilise helpful coping strategies, social supports, and to enhance their natural resilience in the face of trauma.

One unknown aspect of applying evidence-based practice for these parents is how effective the approach would be with traumatic stressors that are recurrent as opposed to post. With the definition of DSM-5 PTSD Criterion A expanding to include repeated or extreme indirect exposure to aversive details of an event (e.g.,
first responders) it is hoped that research exploring the impact of frequent and recurrent exposure to traumatic stressors, and subsequent treatment, will soon accumulate.

7.1.4 Future research

The findings of this thesis contributes to our evolving understanding of parenting stress amongst parents of children with ASD and, more specifically, the validity of using a traumatic stress framework within this population. Nevertheless, this line of enquiry is in its infancy and thus many questions remain unanswered. The following section will outline four research aims that would extend upon the studies conducted as part of this thesis.

The first aim is to investigate PTSD psychopathology in parents of children with ASD. This research would build upon the online questionnaire format by utilising gold standard clinical interview measures (e.g., Clinician-Administered PTSD scale for DSM-5; Weathers et al., 2013) to follow-up with parents who reported high levels of trauma symptomatology required for consideration of a PTSD diagnosis. A follow-up with these parents would allow researchers to confirm whether or not the parent is being exposed to a Criterion A traumatic stressor while also gaining a better understanding of how traumatic stress may present itself in parents of children with ASD. This research would begin to inform specialist mental health services while also providing early insight into PTSD prevalence rates in parents of children with ASD.

The second aim is to investigate the unaccounted for variance in parents’ trauma scores on the PTSD Checklist. With around a third of this variance explained by challenging child behaviours, a further two thirds remains unexplained. Factors
that may account for additional variance include pre-existing or comorbid mental health conditions in families (including siblings of identified child with ASD), level of social support (from a partner, family/friends, or professionals), access to respite care, and socioeconomic variables.

The third aim that extends upon the studies comprising this thesis is to explore whether fathers of children with ASD report similar trauma symptomatology to mothers. Despite the low participation rate of fathers in our studies, one of the seven fathers who provided data via the online survey met the DSM-5 PTSD diagnostic criteria required for consideration of provisional PTSD based on the PTSD Checklist measure. Further research with fathers is required to better understand how they may experience trauma symptomatology and to address their consistent and conspicuous “absence” in the relevant literature.

Prior research indicates that fathers may experience less mental health problems overall than mothers of children with ASD (e.g., Hastings et al., 2005; Sharpley, Bitsika, & Efremidis, 1997), although this may be at least partly explained by the fact that they are less often the primary caregiver. Furthermore, fathers are also reported to employ more avoidant coping strategies than mothers, which is hypothesised to result in decreased engagement with their child. However, when exploring traumatic stress, Seltzer et al. (2010) found that, although parent gender influenced what child behaviours were perceived as challenging, both genders exhibited cortisol profiles consistent with chronic stress, as seen in individuals diagnosed with PTSD. Developing a clearer understanding as to whether there is a differential pattern of predictors for PTSD symptomatology across gender will support the development of tailored support for both parents.
The final aim that arises from the results presented in this thesis is to explore the validity of applying a traumatic stress framework with another population of parents who are raising children with challenging behaviours. This would help elucidate whether these early findings are specific to parents of children with ASD, or whether there are other subpopulations of parents that may also benefit from increased awareness of posttraumatic stress symptoms and PTSD diagnoses. For example, research suggests that parents of children with rare diseases (defined as conditions that effect less than 5% of the world population; EURODIS, 2005) encounter practical and emotional challenges, including poor community and health professional understanding, feelings of anger and denial, volatility of their child’s health and behaviour, and social isolation (Anderson, Elliott, & Zurynski, 2013; Pelentsov, Laws, & Esterman, 2015). They may therefore be another identifiable parent population at risk of elevated levels of traumatic stress.

### 7.1.5 Conclusion

This thesis addresses a gap in the body of knowledge relating to a clinical understanding of elevated stress in parents of children with ASD. The aim of this thesis was to investigate the validity of defining elevated stress within a traumatic stress framework. Results from the studies undertaken demonstrated support for the validity of adopting a traumatic stress framework to conceptualise the mental health symptoms experienced by a subpopulation of parents of children with ASD. Further empirical research is warranted to address the identified limitations of the presented studies and to continue advancing our understanding of trauma responses in this population and, ultimately, to identify best-practice supports for them.
References


Yehuda, R., Boisoneau, D., Lowy, M. T., & Giller, E. L. (1995). Dose-response changes in plasma cortisol and lymphocyte glucocorticoid receptors following dexamethasone administration in combat veterans with and without


Appendices
Appendix One (Chapter 5)
Qualitative research flyer

The experience of parenting a child with an autism spectrum disorder

Parenting a child with an autistic spectrum disorder can be rewarding and challenging. We would like to invite parents to participate in a focus group (with approximately five other parents) to share the challenges they encounter as part of their parenting journey.

This study is being conducted by researchers at Deakin University. The aims of this study are to gain an in depth understanding of how parents experience challenges, whether some experiences lead to the development of significantly elevated stress levels, and what type of stress parents report. This is an area which has been largely neglected, thus information from these focus groups will aid in guiding future research and increasing awareness of the importance of parent mental health.

Who? Parents of children aged 6 to 18 who have a diagnosis of an autism spectrum disorder.

Participation? 60 to 90 minutes of your time to take part in a focus group at Deakin University, Burwood Campus. Refreshments and food will be provided and each participant will receive a $20 Coles/Myer gift card to thank them for their time.

Any information provided by participants will be treated in the strictest of confidence and participants will not be individually identifiable in the resulting report. Participants are free to discontinue participation at any time or to decline to answer particular questions.

This study forms part of Michelle Stewart’s Doctoral thesis, which is being supervised by Associate Professor David Austin. This study has been approved by the Deakin University Human Research Ethics Committee (2013-292). If you are interested in participating or would like additional information please contact Michelle Stewart at michelle.stewart@deakin.edu.au
Qualitative study plain language statement

PLAIN LANGUAGE STATEMENT AND CONSENT FORM

TO: parents and guardians

Plain Language Statement

Date: 9th November 2013

Full Project Title: A qualitative exploration of the lived experience of parenting a child with autism

Principal Researcher: Associate Professor David Austin

Student Researcher: Michelle Stewart

Associate Researcher(s): Associate Professor Jane McGillivray

The purpose of this study is to learn more about the challenges of parenting a child who has an autism spectrum disorder. Parenting a child with autism can lead to daily challenges which increase stress for parents. The present study aims to gain an in depth understanding of the challenges parents face, and what type of stress parents experience. An understanding of how parent mental health may be impacted by the parenting experience is important as it will help to inform support services.

Participants will take part in a focus group at the Bunyong Campus of Deakin University with approximately five other parents. Upon arrival participants will receive a name tag and have the chance to meet the other participants over some refreshments. The focus group will run for 60 to 90 minutes, and during this time participants will be invited to share some of their experiences. The facilitator of the focus group may ask questions of the group throughout the session and participants are free to choose whether they would like to respond. An example of a question which may be asked includes 'what sorts of behavior does your child engage in which you find most challenging as a parent?' There will be an audio recording of the focus group session to allow for the creation of a transcript.
It is hoped that the experience of sharing and hearing other parent’s stories will be a meaningful experience for all participants. Participants may potentially experience some discomfort when either sharing or hearing other parent’s stories. The researchers anticipate a supportive group environment and one of the researchers is an experienced psychologist who will be available to provide additional support if required. Although prolonged emotions which may cause discomfort or distress are not anticipated, contact details for both researchers will be provided to each participant in the event they wish to seek support.

The insight gained from listening to parents talk about the challenges associated with parenting will provide essential information to further investigate the type of stress parents may experience when raising their child. This area of research has been largely ignored, thus contributions from participants will aid in guiding future research, increasing awareness of the importance of parent mental health, and determining the best way to support parents who experience elevated stress symptoms. These outcomes will in turn benefit the entire family.

The audio recording and subsequent transcripts from the focus group will only be accessible by the primary researchers. Numbers will be assigned to participants in the creation of the transcript as opposed to first names. Copies of this information will be stored in the primary researcher’s filing cabinet which will be locked during the entire duration of the research project. The collected information will be securely stored at the School of Psychology at Deakin University for a period of five years, independent of any particular researcher’s tenure, and then destroyed. This is standard protocol for the School of Psychology.

The form of dissemination of the research results, including publications, will not identify any participants by name. Participants will be provided with the contact details of the primary researchers and the Deakin University Human Research Ethics Committee if they wish to discuss any aspect of participation in this research. Participants will also have the opportunity to request access to the results from this study.

Participants will be provided with a $20 Coles/Myer gift card to thank them for their time at the conclusion of the focus group.

Participants are free to withdraw from participating at any stage prior to the focus group commencing or during the focus group; however given the audio of the focus groups will be recorded it will not be possible to withdraw their data.
The researchers involved in this project anticipate conducting future studies which will be informed by the information derived from the focus groups. If you are interested in being contacted at a later stage regarding future studies relevant to this topic, please provide your consent to be sent information.

Contact details of the researchers:

A/Prof David Austin
221 Burwood Highway
Burwood 3125
03 9251 7227
david.austin@deakin.edu.au

Michelle Stewart
221 Burwood Highway
Burwood 3125
03 9021 2222
michelle.stewart@deakin.edu.au

Complaints

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact:

The Manager, Research Integrity, Deakin University, 221 Burwood Highway, Burwood Victoria 3125. Telephone: 9251 7129, research-ethics@deakin.edu.au

Please quote project number [2013-292].
PLAIN LANGUAGE STATEMENT AND CONSENT FORM

TO: parents and guardians

Consent Form

Date:

Full Project Title: A qualitative exploration of the lived experience of parenting a child with autism

Reference Number: 2013-292

I have read, and I understand the attached Plain Language Statement.

I freely agree to participate in this project according to the conditions in the Plain Language Statement. I understand that the audio from the focus group will be recorded to allow for the creation of a transcript. The researchers have agreed not to reveal my identity and personal details, including where information about this project is published, or presented in any public form.

I have been given a copy of the Plain Language Statement and Consent Form to keep.

Participant’s Name (printed) ..................................................................................................................................................

Signature ............................................................................................ Date ..................................

☐ Please tick this box if you consent to being contacted about the next stage of this research project. Please provide your preferred method of future contact:

Email ................................................................................................... and/or Phone .................................................................

A/Prof David Austin
221 Burwood Highway
Burwood 3125
03 9251 7227
david.austin@deakin.edu.au

Michelle Stewart
221 Burwood Highway
Burwood 3125
03 9621 2222
michelle.stewart@deakin.edu.au
PLAIN LANGUAGE STATEMENT AND CONSENT FORM

TO: parents and guardians

Withdrawal of Consent Form

Date:

Full Project Title: A qualitative exploration of the lived experience of parenting a child with autism

Reference Number: 2013-292

I hereby wish to WITHDRAW my consent to participate in the above research project and understand that such withdrawal WILL NOT jeopardise my relationship with Deakin University.

I understand that I am free to withdraw from participating at any stage prior to the focus group commencing or during the focus group. I understand that if I withdraw from participating during the focus group any data collected as part of the audio recording cannot be withdrawn.

Participant’s Name (printed) ..........................................................

Signature ........................................................................ Date ...............

Please mail or email this form to:

Michelle Stewart
221 Burwood Highway
Burwood 3125
michelle.stewart@deakin.edu.au

Plain Language Statement & Consent Form to Parent or guardian
[Project ID 2013-292]: version 2: 17/12/2013
Appendix Two (Chapter 6)

Quantitative study recruitment flyer

We are interested in understanding how difficult, distressing and challenging behaviours exhibited by children can psychologically impact a parent.

Our aim is to expand the current understanding of ‘parenting stress’ and raise awareness for the importance of parent mental health.

Who are we looking for?
Parents of a child aged 5 to 20 years with an Autism Spectrum Disorder OR without a diagnosis or disability

What’s involved?
Thirty minutes of your time to complete an online questionnaire.

You will be entered into a draw to receive 1 of 8 $50 shopping vouchers (your choice of Amazon, Coles, Myer or Bunnings) to thank you for your help with this research.

WEBSITE LINK

The project has been approved by the Human Research Ethics Committee of Deakin University (2014-043).

It is being undertaken by Stephlea Strowell (Doctor of Clinical Psychology, student) and the primary supervisor for the research project is Associate Professor David Asstein.
Online quantitative study plain language statement (parent of child with ASD)

School of Psychology
Plain Language Statement

Project Title: An investigation of the psychological impact of parenting a child with challenging behaviours
Principal Researcher: Associate Professor David Austin
Student Researcher: Mrs Michelle Stewart
Associate Researcher(s): Associate Professor Jane McGillivray and Professor David Forbes

Parents who have a child aged 5 to 20 with an Autism Spectrum Disorder are invited to take part in this research project which involves completing an online questionnaire that will take approximately 30 minutes.

You will be asked questions relating to your child’s diagnosis (e.g., what kind of health practitioner provided the diagnosis, age of diagnosis), behaviours your child exhibits which you find most challenging (e.g., self-injurious behaviour, repetitive behaviours, unpredictable actions), and how these challenging behaviours impact you by rating how true various statements are (e.g., “I feel down-hearted and blue”, “I find it hard to unwind”). You will also be asked a series of questions to see whether you have experienced or witnessed difficult or stressful events that sometimes happen to people (e.g., natural disaster, serious accident at work, life-threatening illness).

In addition to answering these questions, you will be asked to provide your first name and email address so that Michelle Stewart has the opportunity to contact you to extend an invitation to participate in the second phase of this project. The second phase of this project involves a telephone interview which will further enrich our understanding of your parenting experience and provide us with an opportunity to explore any elevated levels of stress you may have reported in the online questionnaire.

The information you share with us for this research project is critical for the development of a new framework which we anticipate will better encapsulate some parents’ experiences of raising a child with autism. Furthermore, we expect this project to increase awareness of the importance of parent mental health, both in research and in clinical practice.

Once you have completed the online questionnaire, your contact details will be entered into a draw to receive 1 of 8 $40 gift vouchers (your choice of Coles-Meyer, Amazon, Bunnings, Masters).

Possible Benefits
Although it is not anticipated that you will directly benefit from this research, your contribution will help to inform a greater understanding of some of the challenges faced by
parents raising children with autism and raise awareness for the importance of parent mental health.

Possible Risks
There is a risk that you may experience discomfort or distress while responding. Your participation is voluntary, thus if you feel at any point that you would like to discontinue answering questions you are free to do so. You are also free to decline to answer a specific question. Should you feel the need, counselling services can be obtained through Lifeline on 13 11 14.

Results of Project
The form of dissemination of the research results, including publications, will not identify any participants by name. Participants will be provided with the contact details of the primary researchers and the Deakin University Human Research Ethics Committee should they wish to discuss any aspect of participation in this research. Participants will also have the opportunity to request access to the results from this study.

Participation is Voluntary
Participation is voluntary, thus if you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project within two weeks of participating by contacting Michelle Stewart. Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your relationship with Deakin University or the researchers involved in this project.

Privacy, Confidentiality and Disclosure of Information
The collected data from the online questionnaire will stored on a password protected server and will only be accessible by A/Prof David Austin and Michelle Stewart. This data will be transformed by replacing participants’ first names with unique identifying numbers to increase the level of anonymity. Original data and the unique identified data will be stored in two separate electronic locations. The data from this project will be stored for 5 years after its completion, at which time it will be destroyed.

Ethical Guidelines
This project will be carried out according to the National Statement on Ethical Conduct in Human Research (2007) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies. The ethics aspects of this research project have been approved by the Human Research Ethics Committee of Deakin University (project number 2014-043).
**Complaints**
If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact:

The Manager  
Office of Research Integrity  
Deakin University  
221 Burwood Highway, Burwood, Victoria 3125  
Phone: 03 9251 7129  
Facsimile: 03 9244 6581  
Email: research-ethics@deakin.edu.au

Please quote project number **2014-043**

**Contact details of the researchers:**
Associate Professor David Austin  
221 Burwood Highway, Burwood VIC 3125  
Phone: 03 9251 7227  
Email: david.austin@deakin.edu.au

Michelle Stewart  
221 Burwood Highway, Burwood VIC 3125  
Phone: 03 9021 2222  
Email: michelle.stewart@deakin.edu.au

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By clicking the "Begin Survey" button below, you are agreeing that you have read and understood the Plain Language Statement and that you are consenting to participate in this research.
Online quantitative study plain language statement (parent of TD child)

**Project Title:** An investigation of the psychological impact of parenting a child with challenging behaviours

**Principal Researcher:** Associate Professor David Austin

**Student Researcher:** Mrs Michelle Stewart

**Associate Researcher(s):** Associate Professor Jane McGillivray and Professor David Forbes

Parents who have a child aged 5 to 20 who are typically developing (i.e. do not have a diagnosed disability) are invited to take part in this research project which involves completing an online questionnaire that will take approximately 30 minutes. You will be asked questions relating to your child’s behaviours and those you find the most challenging (e.g., anti-social behaviours, unpredictable actions, tantrums), and how these challenging behaviours impact you by rating how true various statements are (e.g., “I feel down-hearted and blue”, “I find it hard to unwind”). You will also be asked a series of questions to see whether you have experienced or witnessed difficult or stressful events that sometimes happen to people (e.g., natural disaster, serious accident at work, life-threatening illness).

In addition to answering these questions, you will be asked to provide your first name and email address so that Michelle Stewart has the opportunity to send you a letter to thank you for your participation, and to enter you into the draw to receive 1 of 8 $40 gift vouchers (your choice of Coles Myer, Amazon, Bunnings or Masters voucher).

The information you share in this research project will allow us to gain a better understanding of how parents of children (both with and without disabilities) are psychologically impacted by their child’s challenging behaviours.

**Possible Benefits**

Although it is not anticipated that you will directly benefit from this research, your contribution will help to inform a greater understanding of the challenges faced by parents raising children with challenging behaviours, and to raise awareness for the importance of parent mental health.

**Possible Risks**

There is a risk that you may experience discomfort or distress while responding. Your participation is voluntary, thus if you feel at any point that you would like to discontinue answering questions you are free to do so by closing the browser window. Should you feel the need for counselling services, please contact your local GP, telephone counselling service (Lifeline Australia 13 11 14) or contact the researchers of this project if you require a referral.
Results of Project
The form of dissemination of the research results, including publications, will not identify any participants by name. Participants will be provided with the contact details of the primary researchers and the Deakin University Human Research Ethics Committee should they wish to discuss any aspect of participation in this research. Participants will also have the opportunity to request access to the results from this study.

Participation is Voluntary
Participation is voluntary, thus if you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project within two weeks of participating by contacting Michelle Stewart. Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your relationship with Deakin University or the researchers involved in this project.

Privacy, Confidentiality and Disclosure of Information
The collected data from the online questionnaire will stored on a password protected server and will only be accessible by A/Prof David Austin and Michelle Stewart. This data will be transformed by replacing participants’ first names with unique identifying numbers to increase the level of anonymity. Original data and the unique identified data will be sorted in two separate electronic locations. The data from this project will be stored for 5 years after its completion, at which time it will be destroyed.

Ethical Guidelines
This project will be carried out according to the National Statement on Ethical Conduct in Human Research (2007) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies. The ethics aspects of this research project have been approved by the Human Research Ethics Committee of Deakin University (project number 2014-043).

Complaints
If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact:

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Phone: 03 9251 7129
Facsimile: 03 9244 6581
Email: research-ethics@deakin.edu.au

Please quote project number 2014-043
Contact details of the researchers:
Associate Professor David Austin
221 Burwood Highway, Burwood VIC 3125
Phone: 03 9251 7227
Email: david.austin@deakin.edu.au

Michelle Stewart
221 Burwood Highway, Burwood VIC 3125
Phone: 03 9021 2222
Email: michelle.stewart@deakin.edu.au

By clicking the "Begin Survey" button below, you are agreeing that you have read and understood the Plain Language Statement and that you are consenting to participate in this research.
Online quantitative questionnaire

Thank you for taking an interest in our research. To begin with, can you please provide us with some information about you and your family?

What is your first name?

Please provide at least one of your contact details below to enter into the draw and to potentially receive an invite to participate in a follow-up phone interview:

Email Address?
Contact number?

Your age?
Your gender (male, female, other)?
Do you live in a (metropolitan area, regional area, rural area)?
Are you (married, single, divorced, defacto, widowed, other)?
How many children do you have in total?

For each child:
Year of birth?
Child’s gender (male, female)?
Has this child received any psychological, medical or learning disorder diagnoses?

(Following options only visible to parents of children with ASD)
Professional that diagnosed your child (paediatrician, psychiatrist, psychologist, GP, other)
Diagnosis child received (autism, Aspergers, high functioning autism, PDD-NOS)
**Instructions:** Listed below are a number of difficult or stressful things that sometimes happen to people. For each event check one or more of the boxes to the right to indicate that: (a) it happened to you personally; (b) you witnessed it happen to someone else; (c) you learned about it happening to a close family member or close friend; (d) you were exposed to it as part of your job; (e) you’re not sure if it fits; or (f) it doesn’t apply to you.

Be sure to consider your *entire life* (growing up as well as adulthood) as you go through the list of events.

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<th>Event</th>
<th>Happened to me</th>
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<th>Learned about it</th>
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<td>1. Natural disaster (for example, flood, hurricane, tornado, earthquake)</td>
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<td>2. Fire or explosion</td>
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<td>3. Transportation accident (for example, car accident, boat accident, train wreck, plane crash)</td>
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<td>4. Serious accident at work, home, or during recreational activity</td>
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<td>5. Exposure to toxic substance (for example, dangerous chemicals, radiation)</td>
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<td>6. Physical assault (for example, being attacked, hit, slapped, kicked, beaten up)</td>
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<td>7. Assault with a weapon (for example, being shot, stabbed, threatened with a knife, gun, bomb)</td>
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<td>8. Sexual assault (rape, attempted rape, made to perform any type of sexual act through force or threat of harm)</td>
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<td>9. Other unwanted or uncomfortable sexual experience</td>
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<td>10. Combat or exposure to a war-zone (in the military or as a civilian)</td>
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<tr>
<td>11. Captivity (for example, being kidnapped, abducted, held hostage, prisoner of war)</td>
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</tr>
<tr>
<td>12. Life-threatening illness or injury</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>13. Severe human suffering</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>14. Sudden violent death (for example, homicide, suicide)</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>15. Sudden accidental death</td>
<td></td>
<td></td>
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<tr>
<td>16. Serious injury, harm, or death you caused to someone else</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>17. Any other very stressful event or experience</td>
<td></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>
Next is a list of statements. Please indicate for each statement below the degree to which you believe they have applied to you over the past week. Please do not spend too much time on any one statement.

N = did not apply to me at all/NEVER  
S = Applied to me to some degree/SOMETIMES  
O = Applied to me a considerable degree/OFTEN  
AA = Applied to me very much/ALMOST ALWAYS

<table>
<thead>
<tr>
<th></th>
<th>Statement</th>
<th>N</th>
<th>S</th>
<th>O</th>
<th>AA</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I found it hard to wind down</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2</td>
<td>I was aware of dryness of my mouth</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3</td>
<td>I couldn't seem to experience any positive feeling at all</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4</td>
<td>I experienced breathing difficulty (e.g., excessively rapid breathing, breathlessness in the absence of physical exertion)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5</td>
<td>I found it difficult to work up the initiative to do things</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6</td>
<td>I tended to over-react to situations</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7</td>
<td>I experienced trembling (e.g., in the hands)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>8</td>
<td>I felt that I was using a lot of nervous energy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>9</td>
<td>I was worried about situations in which I might panic and make a fool of myself</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>10</td>
<td>I felt that I had nothing to look forward to</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>11</td>
<td>I found myself getting agitated</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>12</td>
<td>I found it difficult to relax</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>13</td>
<td>I felt down-hearted and blue</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>14</td>
<td>I was intolerant of anything that kept me from getting on with what I was doing</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>15</td>
<td>I felt I was close to panic</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>16</td>
<td>I was unable to become enthusiastic about anything</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>17</td>
<td>I felt I wasn't worth much as a person</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>18</td>
<td>I felt that I was rather touchy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>19</td>
<td>I was aware of the action of my heart in the absence of physical exertion (e.g., sense of heart rate increase, heart missing a beat)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>20</td>
<td>I felt scared without any good reason</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>21</td>
<td>I felt that life was meaningless</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
Some children have difficulties with their emotions and behaviour. These can sometimes be a challenge for their parent/carer. If you have more than one child on the autism spectrum (or if parent completed questionnaire for typically developing child, “if you have more than one child”), please consider the child who exhibits the most challenging behaviours when completing the following checklist.

Many of the following behaviours may not apply to your child. For each item that describes your child, now or within the past six months, please select whether the item is ‘very true or often true’, ‘somewhat or sometimes true’, or ‘not true as far as you know’ of your child. If your child is unable to perform an item, select the ‘not true as far as I know’. For example, if your child has no speech, then for the item “talks too much or too fast” select ‘not true as far as you know’.

<The Developmental Behaviour Checklist (Parent version) was inserted here as part of the online questionnaire. Due to copyright reasons, this instrument has not been reproduced for the appendix. It can be sourced from http://www.med.monash.edu.au/scs/psychiatry/developmental/clinical-research dbc/>
The following is a list of problems that people sometimes have in response to extremely stressful experiences. **Keeping in mind the experience of parenting your child with ASD who exhibits challenging behaviours** (or if parent completed questionnaire for typically developing child, “the experience of parenting your child who exhibits the most challenging behaviours”), please read each difficulty carefully and then select one of the options to indicate how much you have bothered by any of the following difficulties in the past month.

<table>
<thead>
<tr>
<th>Number</th>
<th>Description</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Moderately</th>
<th>Quite a bit</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Repeated, disturbing memories, or unwanted memories, of a stressful experience?</td>
<td></td>
<td></td>
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<tr>
<td>2.</td>
<td>Repeated, disturbing dreams of a stressful experience?</td>
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<tr>
<td>3.</td>
<td>Suddenly acting or feeling as if a stressful experience were happening again (as if you were actually back there reliving it?)</td>
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<tr>
<td>4.</td>
<td>Feeling very upset when something reminded you of a stressful experience?</td>
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<tr>
<td>5.</td>
<td>Having physical reactions when something reminds you of a stressful experience?</td>
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<tr>
<td>6.</td>
<td>Avoiding memories, thoughts or feelings related to a stressful experience?</td>
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<tr>
<td>7.</td>
<td>Avoiding external reminders of a stressful experience (e.g. people, places, conversations, activities, objects or situations)?</td>
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<tr>
<td>8.</td>
<td>Trouble remembering important parts of a stressful experience?</td>
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<tr>
<td>9.</td>
<td>Having strong negative beliefs about yourself, other people, or the world (e.g. having thoughts such as: I am bad, there is something seriously wrong with me, no one can be trusted, the world is completely dangerous)?</td>
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<tr>
<td>10.</td>
<td>Blaming yourself or someone else for a stressful experience or what happened after it?</td>
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<tr>
<td>11.</td>
<td>Having strong negative feelings such as fear, horror, anger, guilt, or shame?</td>
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<tr>
<td>12.</td>
<td>Loss of interest in activities that you used to enjoy?</td>
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<td>13.</td>
<td>Feeling distant and cut off from people?</td>
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<tr>
<td>14.</td>
<td>Trouble experiencing positive feelings (e.g. being unable to feel happiness or have loving feelings for people close to you)</td>
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<tr>
<td>15.</td>
<td>Irritable behaviour, angry outburst, or acting aggressively?</td>
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<tr>
<td>16.</td>
<td>Taking too many risks or doing things that could cause you harm?</td>
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<tr>
<td>17.</td>
<td>Being “super alert” or watchful or on guard?</td>
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<tr>
<td>18.</td>
<td>Feeling jumpy or easily started?</td>
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<tr>
<td>19.</td>
<td>Having difficulty concentrating?</td>
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<tr>
<td>20.</td>
<td>Trouble falling or staying asleep?</td>
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</tbody>
</table>
Thank you for taking the time to share your parenting experiences. The questions you have just completed have been designed to investigate whether a new framework of understanding for the challenges that some parents experience raising a child with autism is feasible. It is hoped this research will raise awareness for the importance of parent mental health.

As a way of thanking you for your time, you have been entered into a draw to receive 1 of 8 $40 shopping vouchers (your choice of Coles-Myer, Amazon, Bunnings, Masters). At the completion of this study the draw will take place and you will be contacted if your name has been drawn.

If you would like to receive a summary of the results from this project, please get in touch with Michelle Stewart, as we would be happy to share what we learn. This project is expected to be completed by December 2015.

You may also be contacted by Michelle Stewart with an invitation to participate in the second phase of this research.

The questions in this survey may have raised some issues about the effect of your child’s behaviours on your life. If you experience any ongoing feelings of discomfort, counselling services can be obtained through your local GP, telephone counselling services (Lifeline Australia 13 11 14) or you may contact the researchers of this project if you require a referral.

If you have any further questions regarding this research, please contact:
Doctoral student research: michelle.stewart@deakin.edu.au
Primary supervisor: david.austin@deakin.edu.au