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The Importance of Considering Trauma in Individuals with Autism Spectrum Disorder: Considerations and Clinical Recommendations

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Autism spectrum disorder (ASD) is an early onset, pervasive, and lifelong neurodevelopmental disorder which is characterised by impairments in social communication and repetitive, restricted behaviour patterns and atypical response to sensory stimuli (DSM-V, American Psychiatric Association, APA, 2013). To date, only one rigorous study of ASD prevalence in adults has been conducted (Brugha et al., 2011). This investigation, which was conducted in England in 2007, produced an estimate of ASD in 1% in the general population which is consistent with the findings from earlier investigations (e.g., Simonoff, 2012). In the general population, the male–female ratio for ASD prevalence is between 4 and 5:1 (Fombonne, 2009). The fifth edition of The Diagnostic Statistical Manual (DSM-V, American Psychiatric Association, APA, 2013) characterises, what was previously three core areas of impairment, two core areas of impairment in ASD: (1) “persistent deficits in social communication and social interaction” and (2) “restricted, repetitive patterns of behavior, interests, or activities” (APA, 2013). Across individuals, impairment to these two core areas of impairment differs with respect to symptoms and severity of symptoms.

Fuld (2018) recently highlighted findings which suggested that individuals with ASD may be at increased risk for experiencing stressful and traumatic life events compared to neurotypical individuals. For example, adult women with ASD report significant sexual abuse with a prevalence rate 2-3 times higher than their peers (Brown-Levoie, Vecili, & Weiss, 2014). Despite high rates of abuse, low rates of posttraumatic stress disorder (PTSD) have been reported (King, 2010). King (2010) suggested that this discrepancy may be accounted for by an individual with ASD, with cognitive and language difficulties, understanding or expressing what occurred, and/or labelling an experience as trauma. Dell’Osso and colleagues (2016) also identified that the difficulties with understanding how trauma is manifested in ASD may also contribute to the low incident of PTSD being diagnosed. PTSD and other trauma and stressor-related disorders in relation to ASD appears to be a relatively under-researched area (Haruvi-Lamdan, Horesh, & Golan, 2018). There has been limited research into the associations and co-morbidity between the two, especially in adults. Each area has developed independently, with the result that each area has significant bodies of theoretical and clinical knowledge (Haruvi-Lamdan et al., 2018). The challenge involves integrating these different bodies of knowledge when possible, but also identifying and proceeding to address pertinent issues specific to the interaction of trauma and ASD.

Vulnerability factors related to trauma for individuals with ASD

Studies indicate that, due to a number of vulnerability factors, individuals with ASD may exhibit more severe emotional reactions to traumatic events (e.g., Dell’Osso, Dalle Luche, & Carmassi, 2015; Hoover, 2015). For

instance, they often may lack the social support networks that have been found to be protective following trauma (Estell et al., 2009). Also, there may be a number of ways in which delays in language development may increase posttraumatic symptomatology in some individuals with ASD. For instance, these difficulties may hinder the reporting of the abuse or posttraumatic distress which causes delay to the possibility of receiving treatment/intervention (Cook Jr, Kieffer, Charak, & Leventhal, 1993). Traumatized individuals with ASD may find it particularly challenging to get involved in traditional trauma-focused therapies, because they may involve the verbal retelling of traumatic narratives and emotional expression. This could be the case both in individual therapy and in a group setting which may be socially demanding. For children with ASD this may be difficult or even impossible (Haruvi-Lamdan et al., 2018).

Possible pathways that may link trauma and ASD

A number of possible different pathways that may link ASD and trauma were recently highlighted by Haruvi-Lamdan, Horesh and Golan (2018). First, ASD may serve as a vulnerability marker for posttraumatic stress disorder (PTSD). It may do this by increasing the risk for exposure to traumatic events (e.g., Taylor & Gotham, 2016; Berg, Shiu, Acharya, Stolbach, & Msall, 2016). Second, once PTSD has appeared it may exacerbate ASD symptoms, for example, through maladaptive coping strategies and reduced help-seeking behaviour. Third, it may be that there exist shared neurobiological mechanisms for PTSD and ASD, including neurological abnormalities associated with both disorders, as well as cognitive and behavioural mechanisms, including increased rumination, cognitive rigidity, avoidance, anger, and aggression. Along similar lines, Im (2016) suggested that individuals with ASD may “possess sensitized prefrontal-cortical-limbic networks that are overloaded in the face of trauma, leading to unchecked limbic output that produces violent behaviour, and/or cognitive dysfunction (including deficits in theory of mind, central coherence, and executive function) that impacts trauma processing in ways that portend violence” (Im, 2016, pp. 184).

Symptoms of trauma may go unrecognised in individuals with ASD

There is an increasing number of studies which have indicated that stressful and traumatic life events are an underlying risk factor for the vast majority of the comorbid psychopathologies which have been found to be most common in individuals with ASD (Mannion, Brahm, & Leader, 2014). Moreover, exposure to stressful and potentially traumatic events may be exhibited as symptoms of aggression, concentration difficulties, social isolation, increased relational difficulties, regression in daily living skills, and an increase in the levels of repetitive or stereotypic behaviour (e.g., Bishop-Fitzpatrick, Mazefsky, Minshew, & Eack, 2015). Because a lot

of these symptoms are commonly associated with ASD, professionals may assess them as part of the ASD diagnosis. Thus, the stress and/or trauma underlying these symptoms remains unidentified and untreated (Kerns, Newschaffer, & Berkowitz, 2015). Therefore, it is important that clinical professionals are aware of this when carrying out assessments, functional assessments and also when they are engaging in case consultations, and contributing to treatment and treatment planning.

The unique posttraumatic clinical picture in individuals with ASD

There is evidence which indicates that, when compared with typically developing individuals, individuals with ASD may exhibit symptoms of traumatic stress in a ‘distinct manner’ (Haruvi-Lamdan et al., 2018). The literature regarding trauma and adults with ASD primarily involves case reports that present varying post-trauma symptoms. For instance, Weiss and Lunsky (2010) presented the case of an adult in her mid-30s with Asperger’s Syndrome. Post trauma exposure resulted in such symptoms as intrusive memories and flashbacks, often feeling angry and trapped, trying to put it out of her mind, and having intense distress to trauma reminders. Kosatka and Ona (2014) reported on a case of a 21-year-old with asperger’s syndrome who also presented with the avoidance of strangers, difficulties sleeping and anhedonia. Carrigan and Allez (2017) used both a clinician assessment and the 26 year old’s self-report and identified such PTSD symptoms including having arguments with parents, angry outbursts and reduced time spent outside the house in the community due to feeling threatened, a belief that people are out to get him and not to be trusted, blaming himself for trauma, difficulties falling and staying asleep, remaining alert for threats, avoiding the location where the attack happened, suppressing trauma memories and flashbacks, and concerns that the trauma symptoms were a sign of madness.

The need for the development of validated clinical tools to identify and assess traumatic and stressful life events in individuals with ASD: A suggested approach in identifying trauma and assessing changes in functioning

There is a need for validated clinical tools to identify and examine traumatic and stressful life events in adults with ASD. The assessment scales which have been used in the research studies on ASD and trauma (Mehtar & Mukaddes, 2011; Taylor & Gotham, 2016) could prove to be particularly useful clinical tools to support clinicians and other professionals when conducting trauma focused assessments with individuals with ASD (Fuld, 2018). An additional benefit of using this approach would be to help identify traumatic experiences, and especially abusive experiences, so that proper follow up forensic and criminal investigations can occur. For these reasons, it may be appropriate for examiners to have to *rule out the occurrences of traumatic stressors* when evaluating individuals with an ASD and have to actively seek information that would rule out these experiences, rather than the usual practice of ruling them in during clinical and forensic evaluations. Kerns and colleagues (2015) highlight the need to address the lack of appropriate and valid measures for this population. For instance,

Mehtar and Mukaddes (2011) developed, what they called, the Trauma Symptoms Investigation Form in Autistic Spectrum Disorders (TIF-ASD, see Mehtar & Mukaddes, 2011), which examines changes in verbal communication, behavioural problems, stereotypical and ritualistic behaviours, self-care skills, and vegetative symptoms. The aim of this form is to examine the effect of traumatic events on core symptoms of ASD as well as other associated behavioural features. It assesses the course of symptoms in five separate categories in the following six months period of trauma exposure. The form is completed based on parents' feedback and retrospective analysis of records of those with a positive history of trauma. The ASD-TIF comprises of five separate categories and 20 items scored on a three level rating system, namely, 'increase', 'decrease' and 'no change'. The items cover: social and communication skills (eye contact, response to calling name, interaction with surrounding, imitation skills, sharing with people, peers relationship, and verbal communication: echolalia, perseveration and neologism; items: 1–4, 6, and 7), behavioural problems (aggressiveness, anger bursts, mood changes, agitation, distractibility, apathy, self/others' harm and destructive behaviour, activity level, and incompatibility; items 5, 8, and 13–17), stereotypical and ritualistic behaviours (stereotypic movements, rituals, obsessions, resistance to change; items: 9–12), self-care skills (enuresis, encopresis; item: 20), and vegetative symptoms (appetite, sleep; items: 18 and 19). Future research studies could examine the reliability and validity of this new measure for use in the forensic and clinical setting.

Clinical experience involving work with adult males with ASD (and average IQ and mild adaptive deficits), who are in secure facilities due to violence, suggests that the procedure recommended by the Diagnostic Manual-Intellectual Disability (DM-ID, Fletcher, Loschen, Stavrakaki, & First, 2007) can be utilised when identifying, investigating and understanding trauma in adults with ASD. The DM-ID guidelines recommend first identifying traumatic events, followed by assessing changes in functioning after exposure to these events; this procedure was also suggested by Kerns, Newsschaffer and Berkowitz (2015) and Stavropoulos, Bolourian and Blacher (2018) rather than “the presence or absence of symptoms in isolation” when examining PTSD and ASD (pp.8) in children. Subsequently, clinical presentations for symptoms consistent with the re-experiencing, avoidance, and arousal should be considered and evaluated. Due to the absence of specific guidelines for assessing trauma in individuals with an ASD, clinical experience suggests that the approach recommended by DM-ID may be a starting point for clinicians.

It is important to highlight that, while the use of tools is helpful, it is important that they are used together with good clinical judgment. Future research studies could examine the reliability and validity of this new measure for use in the forensic and clinical setting.

Conclusion

It has been presented that clinical experience with the procedure advocated by the DM-ID for use in identification of traumas and abuse, and the resultant changes in functioning for adults with an Intellectual Disability, could also be used for adults with an ASD. This guideline addresses two of three essential areas, namely how traumas can be better identified, and subsequent to their identification, how changes in functioning can be assessed, rather than just the more typical identification or absence of current symptoms. Additionally, this guideline may also improve the reporting of abuse and trauma, especially if clinicians seek to rule out trauma, as opposed to the more traditional approach to rule it in, due to the substantial abuse that occurs with individuals with ASD and its under-identification. Addressing how trauma manifests in adults with ASD presents with a more current substantial challenge. There is an urgent need for further research exploring the association between trauma and ASD. Future research is needed to investigate the potentially unique perception of traumatic events (most notably from the social domain) in people with ASD (Haruvi-Lamdan et al., 2018) and also explore the possibility and ways in which individuals with ASD may manifest symptoms of traumatic stress in a distinct manner compared to typically developing individuals and the traditional diagnostic criteria for PTSD (Kerns, Newschaffer, & Berkowitz, 2015). This is critical to the identification of trauma in individuals with ASD and further our understanding of posttraumatic clinical picture in individuals with ASD to understand whether there are unique symptom profiles among this population and subsequently help inform appropriate treatment strategies and support (Haruvi-Lamdan et al., 2018). Additionally, it would be helpful to identify when trauma(s) are experienced if appropriate adaptive and even increases in functioning (i.e., resilience after trauma) occurs, and if factors associated with resilience to PTSD for neuro-typical individuals also occurs for adults with ASD.

Research regarding resilience after trauma currently is a neglected area of research for individuals with an ASD. As highlighted by Kerns and colleagues, there remains a number of research questions which require investigation. For instance, research looking at the impact of traumatic events on the short and long-term functioning of individuals with ASD. Also, another line of investigation would be exploring how the acute and prolonged symptoms of trauma are exhibited in individuals with ASD and also how these symptoms interact with key features of ASD to impact on and influence learning and development (Kerns et al., 2015). Lastly, Kerns and colleagues (2015) have recommended that this research should be directly informed by individuals with ASD, their families and supporters. As emphasised recently by Haruvi-Lamdan and colleagues (2018), to date, there is no intervention programme which focuses on targeting PTSD-ASD co-morbidity. As this paper emphasises, there is a real need to address this. Research to date indicates that because of the symptom overlaps between ASD and PTSD, it is possible that individuals with ASD are exhibited traumatic related.

Implications for Practice

- Once PTSD has appeared it may exacerbate ASD symptoms, for example, through maladaptive coping strategies and reduced help-seeking behaviour.
- Due to a number of vulnerability factors, individuals with ASD may exhibit more severe emotional reactions to traumatic events.
- The Diagnostic Manual-Intellectual Disability (DM-ID, Fletcher, Loschen, Stavrakaki, & First, 2007) can be utilised when identifying, investigating and understanding trauma in adults with ASD. The DM-ID guidelines recommend first identifying traumatic events, followed by assessing changes in functioning after exposure to these events.
- Mehtar and Mukaddes (2011) developed, what they called, the Trauma Symptoms Investigation Form in Autistic Spectrum Disorders (TIF-ASD, see Mehtar & Mukaddes, 2011), which examines changes in verbal communication, behavioural problems, stereotypical and ritualistic behaviours, self-care skills, and vegetative symptoms. The aim of this form is to examine the effect of traumatic events on core symptoms of ASD as well as other associated behavioural features.
- It is important to highlight that, while the use of tools is helpful, it is important that they are used together with good clinical judgment.

Conflicts of Interest

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References

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author.

Berg, K. L., Shiu, C. S., Acharya, K., Stolbach, B. C., & Msall, M. E. (2016). Disparities in adversity among children with autism spectrum disorder: A population based study. *Developmental Medicine and Child Neurology*, 58, 1124–1131.

Bishop-Fitzpatrick, L., Mazefsky, C. A., Minshew, N. J., & Eack, S. M. (2015). The relationship between stress and social functioning in adults with autism spectrum disorder and without intellectual disability. *Autism Research*, 8(2), 164-173.

Brown-Lavoie, S. M., Vecili, M. A., & Weiss, J. A. (2014). Sexual knowledge and victimization in adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 44(9), 2185-2196.

Brugha, T. S., McManus, S., Bankart, J., Scott, F., Purdon, S., Smith, J., ... & Meltzer, H. (2011). Epidemiology of autism spectrum disorders in adults in the community in England. *Archives of General Psychiatry*, 68(5), 459-465.

Carrigan, N., & Allez, K. (2017). Cognitive Behaviour Therapy for Post-Traumatic Stress Disorder in a person with an Autism Spectrum Condition and Intellectual Disability: A Case Study. *Journal of Applied Research in Intellectual Disabilities*, 30(2), 326-335.

Cook Jr, E. H., Kieffer, J. E., Charak, D. A., & Leventhal, B. L. (1993). Autistic disorder and post-traumatic stress disorder. *Journal of the American Academy of Child and Adolescent Psychiatry*, 32(6), 1292-1294.

Dell'Osso, L., Gesi, C., & Carmassi, C. (2016). Suicide and autism spectrum disorder: The role of trauma. *Journal of Psychopathology*, 22(2), 107-109.

Dell'Osso, L., Dalle Luche, R., & Carmassi, C. (2015). A new perspective in post-traumatic stress disorder: which role for unrecognized autism spectrum. *Int J Emerg Ment Health*, 17(2), 436-438.

- Estell, D. B., Farmer, T. W., Irvin, M. J., Crowther, A., Akos, P., & Boudah, D. J. (2009). Students with exceptionalities and the peer group context of bullying and victimization in late elementary school. *Journal of Child and Family Studies, 18*(2), 136-150.
- Fletcher, R. E., Loschen, E. E., Stavrakaki, C. E., & First, M. E. (2007). Diagnostic manual--intellectual disability: A textbook of diagnosis of mental disorders in persons with intellectual disability. National Association for the Dually Diagnosed.
- Fombonne, E. (2009). Epidemiology of pervasive developmental disorders. *Pediatric Research, 65*(6), 591-598.
- Fuld, S. (2018). Autism spectrum disorder: the impact of stressful and traumatic life events and implications for clinical practice. *Clinical Social Work Journal, 46*(3), 210-219.
- Haruvi-Lamdan, N., Horesh, D., & Golan, O. (2018). PTSD and autism spectrum disorder: Co-morbidity, gaps in research, and potential shared mechanisms. *Psychological trauma: theory, research, practice, and policy, 10*(3), 290.
- Hoover, D. W. (2015). The effects of psychological trauma on children with autism spectrum disorders: A research review. *Review Journal of Autism and Developmental Disorders, 2*(3), 287-299.
- Im, D. S. (2016). Trauma as a contributor to violence in autism spectrum disorder. *Journal of the American Academy of Psychiatry and the Law Online, 44*(2), 184-192.
- Kerns, C. M., Newschaffer, C. J., & Berkowitz, S. J. (2015). Traumatic childhood events and autism spectrum disorder. *Journal of Autism and Developmental Disorders, 45*(11), 3475-3486.
- Kerns, C. M., & Kendall, P. C. (2012). The presentation and classification of anxiety in autism spectrum disorder. *Clinical Psychology: Science and Practice, 19*(4), 323-347.
- King, R., & Desaulnier, C. L. (2011). Commentary: Complex post-traumatic stress disorder. Implications for individuals with autism spectrum disorders-Part II. *Journal on Developmental Disabilities, 17*(1), 47.
- Kosatka, D., & Ona, C. (2014). Eye movement desensitization and reprocessing in a patient with Asperger's disorder: case report. *Journal of EMDR Practice and Research, 8*(1), 13-18.

Mannion, A., Brahm, M., & Leader, G. (2014). Comorbid psychopathology in autism spectrum disorder. *Review Journal of Autism and Developmental Disorders, 1*(2), 124-134.

Mehtar, M., & Mukaddes, N. M. (2011). Posttraumatic stress disorder in individuals with diagnosis of autistic spectrum disorders. *Research in Autism Spectrum Disorders, 5*(1), 539-546.

Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child and Adolescent Psychiatry, 47*(8), 921-929.

Stavropoulos, K., Bolourian, Y., & Blacher, J. (2018). Differential Diagnosis of Autism Spectrum Disorder and Post Traumatic Stress Disorder: Two Clinical Cases. *Journal of Clinical Medicine, 7*(4), 71.

Taylor, J. L., & Gotham, K. O. (2016). Cumulative life events, traumatic experiences, and psychiatric symptomatology in transition-aged youth with autism spectrum disorder. *Journal of Neurodevelopmental Disorders, 8*(1), 28.

Weiss, J. A., & Lunsky, Y. (2010). Group cognitive behaviour therapy for adults with Asperger syndrome and anxiety or mood disorder: a case series. *Clinical Psychology and Psychotherapy, 17*(5), 438-446.