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CASE REPORT



Post-traumatic stress disorder symptom manifestations in an autistic man with severe intellectual disability following coercion and scalding

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ABSTRACT

Background: Autistic adults with intellectual disabilities (ID) seem to be particularly vulnerable to potentially traumatic experiences and post-traumatic stress disorder (PTSD). Furthermore, this population may be at risk for a different set of traumatic experiences than the general population. However, knowledge is sparse concerning PTSD symptom manifestations in individuals with severe ID.

Method: Exploration of PTSD symptom trajectories and manifestations in an adult, autistic man with severe ID.

Results: Altered arousal/reactivity and problematic avoidance were the most easily observable symptoms. Avoidance seemed to become more generalised over time, and the impact of PTSD on behaviour, level of functioning, and quality of life was severe.

Conclusions: Negligence and coercion in services for autistic adults with ID may involve a traumatic potential for these individuals. Increased awareness of this risk is needed in service providers and mental health professionals.

KEYWORDS

Autism; intellectual disability; PTSD; post-traumatic stress disorder

Autistic individuals with co-occurring intellectual disabilities (ID) are more frequently exposed to potentially traumatic experiences (Daveney et al., 2019; Fogden et al., 2016; Kildahl et al., 2019) and may be more vulnerable to developing post-traumatic stress disorder (PTSD; Haruvi-Lamdan et al., 2020; Mason-Roberts et al., 2018; Rittmannsberger, Weber et al., 2020; Rumball et al., 2020, 2021). The current DSM-5 criteria for PTSD include four symptom groups (American Psychiatric Association, 2013): Intrusion/re-experiencing, avoidance, negative alterations in mood/cognition, and alterations in arousal/reactivity. However, knowledge regarding the identification of PTSD in this population is limited, particularly for individuals with severe/profound levels of ID (Daveney et al., 2019; Kildahl et al., 2019; Mevissen et al., 2016; Rumball, 2019), and knowledge concerning PTSD in individuals with mild/moderate ID may not be generalisable to individuals with severe ID and limited verbal language skills (Kildahl, Oddli et al., 2020).

Due to symptom surface similarities with the underlying condition(s) and lack of appropriate assessment tools and adaptations of diagnostic criteria, identification of mental disorders is generally challenging in autistic adults with ID (Bakken et al.,

2016; Helverschou et al., 2011). Furthermore, these individuals may have difficulties verbally reporting trauma, and PTSD symptoms may manifest in atypical ways, including as “challenging” behaviours (Kildahl et al., 2020a, 2020b; McNally et al., 2021; Mevissen et al., 2016). Diagnostic overshadowing (Reiss et al., 1982), where symptoms of mental disorder are misattributed to autism/ID, may be an issue for PTSD in particular, as the symptoms that seem to be most easily observable (altered arousal/reactivity and negatively altered cognition/mood) are not specific to PTSD (Kildahl et al., 2019; Kildahl et al., 2020b). These symptoms may also be misinterpreted as anxiety/depression, psychosis, or “challenging” behaviours (Daveney et al., 2019; Kildahl et al., 2020b; Mevissen et al., 2016; Rittmannsberger, Yanagida, et al., 2020).

Moreover, because autistic individuals with severe/profound ID frequently depend on services and care in their daily lives, these individuals may be at risk for a different set of traumatic experiences than the general population (Daveney et al., 2019; Kildahl et al., 2020a; McNally et al., 2021). The aim of the current study was to explore the manifestations/trajectories of PTSD symptoms in an adult, autistic male with severe ID,

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following exposure to care-related potentially traumatic events.

Methods

As suggested by Kildahl, Oddli, et al. (2020), case studies (Yin, 2014) are likely to be helpful in further exploration of PTSD symptoms in autistic individuals with severe/profound ID. The study was approved by the Data Protection Official at the Oslo University Hospital (#20/07428). The patient was recruited from a specialised psychiatric department for ID/autism after being diagnosed with PTSD. His legal guardian provided written informed consent for the study, read the manuscript and provided written informed consent for publication.

Case description

“Joseph”, a man in his fifties, was referred to a specialised psychiatric department for ID/autism due to problematic avoidance and “challenging” behaviours. He was diagnosed with autism as a toddler, and his co-occurring ID was specified as severe in adulthood. His verbal language skills were limited to 20–30 words, including names and regularly used idiosyncrasies. He had not been aided by augmentative and alternative communication strategies, and communication with his professional caregivers was mostly based on verbal language and use of concrete objects.

Joseph was reported to have a good childhood in a small village, growing up with his parents and two older sisters. In his twenties, Joseph was described as a happy and well-adjusted young man. He lived with his parents until he was 25, when he moved into a municipal flat getting support from professional caregivers. Joseph’s behaviour changed when he was in his thirties. He started displaying avoidance, which increased over time to encompass more situations and activities. At referral, Joseph stayed almost exclusively in his living room and bedroom, resisting attempts from caregivers at initiating activities.

Assessment

An outpatient assessment was conducted by three experienced mental health professionals (clinical psychologist, psychiatrist, ID nurse) visiting and observing Joseph at home. In addition, his family and caregivers were interviewed using structured assessment tools, and a comprehensive review of his medical and developmental history was undertaken. Autism had previously been thoroughly assessed. The Vineland Adaptive Behavior Scales (Sparrow et al., 2008)

were used for assessment of adaptive functioning; results were in line with the previous diagnosis of severe ID. Psychiatric symptoms were assessed using a combination of direct observation and interviews/assessment tools with Joseph’s parents and caregivers: the Mini neuropsychiatric interview (MINI; Sheehan et al., 1998), the Psychopathology in Autism Checklist (PAC; Helverschou et al., 2009), and the Aberrant Behavior Checklist (ABC; Aman et al., 1985). However, this use of the MINI is not in line with its intended use and results must be interpreted with caution. Somatic and genetic assessment yielded no relevant findings.

During observations, Joseph seemed almost continually anxious and on guard, occasionally displaying apparent panic attacks. Joseph rarely displayed positive emotions, and emotions seemed to fluctuate rapidly. Joseph resisted any activity outside his apartment; putting pressure on him, for instance, trying to get him into a car, could result in Joseph acting out by hitting or kicking his caregivers. During the MINI, parents/caregivers reported previous potentially traumatic experiences, following which they had observed changes to Joseph’s behaviour.

Trauma history

Due to the reports of potentially traumatic experiences and observations that Joseph seemed guarded and anxious, a comprehensive trauma history was obtained using multiple informants. Prior to the initial development of avoidant behaviour, Joseph was to undergo an examination at the local hospital. Joseph resisted and a decision was made to physically coerce Joseph into undergoing the examination. Following this episode, Joseph refused to get into the car that had taken him to the hospital. Avoidance of the specific car subsequently generalised to encompass any car or bus, with Joseph displaying physical aggression if caregivers attempted to take him on car rides. He also developed an apparent phobia of white scrubs and hospital wear.

Three years prior to the current assessment, a caregiver helped Joseph get into the shower and got the water running before leaving him alone for a few moments. When the caregiver returned, Joseph seemed extremely uncomfortable. The water had been too hot, and Joseph suffered second-degree burns on his neck, shoulders and back. Following this episode, Joseph refused to go into the bathroom. He also developed sleep difficulties, waking up during the night seeming frightened and agitated.

Diagnostic formulation – PTSD

Because of Joseph's limited verbal language skills, it was difficult to discern whether he had symptoms involving re-experiencing/intrusive memories. However, nightmares were suspected, and Joseph displayed panic attacks in which he occasionally seemed unresponsive to caregivers' communications. The combination of changed responsivity and altered physiological arousal in the context of physical aggression may indicate the presence of re-experiencing (Kildahl et al., 2020b), as may signs of possible nightmares (McCarthy et al., 2017). Joseph also displayed observable fear reactions to any stimuli involving running water.

As for avoidance, these symptoms seemed to have started with Joseph avoiding stimuli/situations associated with the two experiences. As previously described for autistic adults with ID (Kildahl et al., 2020b), this avoidance subsequently generalised beyond the specific, trauma-related stimuli to entire classes of related stimuli.

Negative changes in mood/cognition were evident by Joseph displaying less positive emotions and frequent mood swings. Negative self image and negative interpretations of others' behaviour were challenging to discern due to Joseph's limited verbal language skills.

Alterations in arousal/reactivity seem to be the most easily observable PTSD symptoms in people like Joseph (Kildahl et al., 2019; Kildahl et al., 2020b), and this was also what struck the clinicians during observation in the current case. Joseph seemed restless, almost continuously displaying signs of hyperarousal. Hypervigilance was observed; Joseph seemed guarded in most interactions with caregivers and preoccupied with getting an overview of their comings and goings. Joseph also displayed reduced sleep quality and frequent panic attacks involving physical aggression (see McNally et al., 2021).

It was concluded that Joseph's traumatic experiences had led to development of altered arousal/reactivity, as well as severe, problematic avoidance. Signs of possible re-experiencing were present in his behaviour, as were negative changes in mood/cognition, resulting in a diagnosis of PTSD. These symptoms had been present following both traumatic experiences but had been particularly intense following the episode involving scalding.

Reports on the ABC and PAC differed somewhat between informants, see Table 1. When Joseph interacted with his family, this occurred in regular, almost scripted visits. Thus, these differences were interpreted as an indication that Joseph's PTSD symptoms were

less intrusive in situations where he felt safe, where he knew what was going to happen, and in which his avoidance was not challenged.

Intervention

Prior to the current assessment, an intervention involving exposure had been attempted by placing desirable objects inside Joseph's bathroom. However, this seemed to increase Joseph's distress and the intervention was discontinued. Following the assessment, treatment strategies were based on trauma-informed care (Keesler, 2014; Truesdale et al., 2019), focusing on safety, autonomy, empowerment, and validation (Bakken et al., 2017) through increasing staff sensitivity to Joseph's communications (Donner & Gustin, 2021; Kildahl et al., 2021). These strategies have contributed to gradually reducing his distress, problematic avoidance, and apparent panic attacks.

Discussion

The current patient was referred for assessment of problematic avoidance and "challenging" behaviour. A comprehensive trauma history unearthed experiences likely to have contributed to development of these behaviours but making this connection required interpreting this problematic behaviour in light of these experiences. Investigating the developmental trajectory of these behaviours and drawing up a time line including his trauma history was helpful in unearthing these connections. The problematic avoidance was in line with previous descriptions of PTSD in this population (Kildahl et al., 2020b), with altered arousal/reactivity being most easily observable and avoidance presenting in a generalised way.

The traumatic experiences had severe impact on the patient's wellbeing and level of functioning, limiting his

Table 1. PAC/ABC scores.

	Parents	Professional caregivers
PAC		
General adjustment difficulties	1.9	2.3*
Psychosis	1.0	2.8*
Depression	2.9*	2.3*
Anxiety	1.8*	2.7*
Obsessive-compulsive disorder	1.0	1.6
ABC		
Irritability/agitation/crying	3	18
Lethargy/social withdrawal	2	15
Stereotypy	2	10
Hyperactivity/noncompliance	7	22
Inappropriate speech	1	9

Note. Psychopathology in Autism Checklist (PAC), Aberrant Behavior Checklist (ABC). PAC scores above cut-off are marked by an asterisk (*).

activities and access to positive experiences. This impact lasted for several years following these experiences and did not diminish over time, highlighting the need for increased awareness to reduce the risk of potentially traumatic experiences in this population, including negligence in services and the use of coercive care strategies (Kildahl et al., 2021; Kildahl et al., 2020a). These findings are in line with previous assertions that trauma-informed care constitutes an essential component in service development for this population (Truesdale et al., 2019) and highlight the importance of exploring the possible causes and trajectories of “challenging” behaviours.

An important basis of exposure therapy is that the level of anxiety at any time is experienced as tolerable and manageable (Lebowitz & Omer, 2013), and this may be challenging to ascertain in patients with limited verbal language skills. In the current case, the previous exposure-based intervention seemed to exacerbate the patient’s symptoms, possibly due to his distress being under-appreciated by caregivers. Emphasising safety, validation, autonomy and empowerment through increasing staff sensitivity (trauma-informed care; Kessler, 2014; Truesdale et al., 2019), however, seems to have been helpful.

The current study concerns a single case and, therefore, has limited generalisability. There may have been other traumatic experiences in the patient’s life, or other mental health or somatic difficulties, not uncovered by the current assessment.

In conclusion, autistic adults with severe ID may be at risk for population-specific experiences involving the risk of trauma and PTSD. PTSD symptoms may have a severe impact on behaviour, level of functioning, and quality of life in this population. Increased awareness in services for these individuals is required to reduce the risk of potentially traumatic experiences occurring due to negligence and use of coercive care strategies, as well as to recognise the impact of such experiences on behaviour, level of functioning, and wellbeing.

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Disclosure statement

No potential conflict of interest was reported by the authors.

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