Elucidating the presentation and identification of PTSD in autistic adults: a modified Delphi study

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Background

Trauma Exposure

Autistic individuals are at higher risk of a range of traumatic experiences

- Criterion A traumas
- Broader traumatic events, particularly social victimisation.

PTSD Symptoms

Probable PTSD rates in autistic adults are 32-45%

Compared to 4-4.5% for non-autistic adults

(Rumball et al., 2020, 2021 Haruvi-Lamdan et al., 2020 Golan et al., 2022)

Clinical Diagnostic Rates

Much lower! (Rumball, 2019; Quinton et al., 2024)

Suggests PTSD may go unrecognised & untreated

- Diagnostic overshadowing
- Misdiagnosis

Lack of validated measures

Lack of clarity re PTSD presentation & idiosynerasies

Lack of clinical confidence

Rationale & Aims

Importance: Where PTSD is missed appropriate treatment, addressing & processing trauma-related memories, is denied.

Rationale: Diagnosis rests on clinical judgement. Need to better understand what informs diagnosis of PTSD in autistic adults.

Aim: Develop professional consensus on identifying and assessing co-occurring PTSD in autistic adults

Methods

Modified Delphi study with three rounds of expert input

Recruitment

Experience of working clinically

with at least one autistic adult (+/-LD)

with suspected or diagnosed PTSD

Round 1

Qualitative data collection

via open-ended Qs from online surveys and interviews.

N=19

Round 2

Statement rating

& qualitative feedback

N=24 (11 new clinicians)

Round 3

Re-rating statements 60-79% consensus

& new statement rating

N=20

Consensus set at ≥ 80% 'agree' or 'strongly agree'

Results

108 consensus statements: Clinical opinions regarding PTSD in autistic adults

Main themes

- 1. Experience of trauma
- 2. Symptoms of trauma & PTSD
- 3. Differential diagnosis
- 4. Assessment methods

Heterogeneity of symptoms: Experience of trauma & PTSD symptoms vary. Statements 'can' be symptoms of PTSD

Experience of trauma

Broad range of events can act as catalysts for PTSD development & should be enquired about

Types of Trauma: Includes traditional (e.g., abuse) and broader events (e.g., sensory overload).

Communication Barriers: Recognising and disclosing trauma.

+LD considerations: risk of traumas associated with daily living, due to caregivers missing signs of distress [as highlighted by work by Kildahl et all

Symptoms of trauma & PTSD

Trauma sequalae: difficulties sleeping, self harm, suicidality

DSM-5 PTSD symptoms are present, but not exhaustive

'Clear Indicators' of PTSD

- Negative & intense reactions to trauma-related triggers/reminders
- Trauma re-experiencing [distinguish from vivid autobiographical recall]
- Trauma-related symptoms that are long-lasting & resistant to change
- aggressive/high-intensity behaviours

Unique Presentations: Some autistic adults may "shut down" rather

Differential Diagnosis

Trauma-relatedness is key!

Misdiagnosis & Diagnostic overshadowing between EUPD & PTSD

Gender Differences: Women may be misdiagnosed with mood/personality disorders, men with anger/behavioural issues.

Increased Autism Characteristics: Trauma can exacerbate autism-related features, but these traits should return to pre-trauma levels with successful trauma treatment [supported by Valenti et al 2011]

Assessment

Clinical Judgement: Validated tools are lacking & presentation varies greatly, clinical judgement remains paramount

Assess trauma-relatedness of symptoms:

- Timeline, Aetiology, Trajectory of symptom development
- Trigger-mapping

Individualised Formulation: personal, systemic, environmental factors

Multi-Method Approach: Use a combination of tools and sources/informants

Communication Aids: Clarify language use tools like DECS where

Limitations

Definition of 'Expert': scarcity of services actively specialising in this area, so opted to include any professional with experience working clinically with this population.

Heterogeneity: PTSD presents differently and consensus statements indicate features/recommendations that 'can' apply.

Is this autism specific?: evidence in general population of non-criterion A events triggering PTSD symptomatology. Unclear re autism-specific PTSD symptom expression.

Future research

Consensus statements:

- Frequency with which different PTSD symptoms occur
- Autistic adults' views on statements generated
- Co-production of training/guides for individuals, families, carers, service providers in recognising varied traumatic experiences, signs of distress and PTSD presentation/trauma-relatedness of symptoms.

And beyond:

- Any autism-specific/idiosyncratic PTSD symptoms
- Develop validated assessment tools
- Efficacy of trauma-focused treatments and best-practice re supporting/treating PTSD for autistic adults

Clinical Implications

Awareness:

- High risk of trauma in autistic adults.
- PTSD symptoms appear to be comparable, but communication of these may require support.

Assessment:

- Enquire about trauma, focus on subjective experience of trauma and assess trauma-relatedness of symptoms/distress.
- Use a multifaceted & formulation-led approach to differentiate PTSD from autism and other conditions.

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