Distinguishing between autism and the consequences of early traumatisation: A case study

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Acknowledgements and Conflict of interest statement

- Thank you to the patient, Rebecca, for sharing her story with us and allowing us and others to learn from it.

- Thank you to Rebecca’s caregivers, who collaborated on the study

- Thank you to the co-authors: Kristin Storvik, Elisabeth Christina Wächter, Tom Jensen, Arvid Ro, Inger Breistein Haugen

- We confirm that the authors have no conflict of interest

Take-home messages

- Autism knowledge is important in services working with people experiencing early adversity
- Autism + trauma may be misdiagnosed as borderline personality disorder (BPD), and this misdiagnosis may exacerbate PTSD symptoms
- Manifestations of autism and complex PTSD do not merely co-occur, but interact, assessment/treatment strategies need to take account of both
- Always try to get information directly from the person concerned, even if it may be challenging

Distinguishing between autism and the consequences of early traumatisation during diagnostic assessment: a clinical case study

Arvid Nikolai Kildahl, Kristin Storvik, Elisabeth Christina Wächter, Tom Jensen, Arvid Ro and Inger Breistein Haugen

Abstract

Purpose – *Distinguishing between autism characteristics and trauma-related symptoms may be clinically challenging, particularly in individuals who have experienced early traumatisation. Previous studies have described a risk that trauma-related symptoms are misinterpreted and/or misattributed to autism. This study aims to describe and explore assessment strategies to distinguish autism and early traumatisation in the case of a young woman with mild intellectual disability.*

Design/methodology/approach – *A clinical case study outlining assessment strategies, diagnostic decision-making and initial intervention.*

Findings – *A multi-informant interdisciplinary assessment using multiple assessment tools, together with a comprehensive review of records from previous assessments and contacts with various services, was helpful in distinguishing between autism and trauma. This included specific assessment tools for autism and trauma. Autism characteristics and trauma-related symptoms appeared to interact, not merely co-occur.*

Originality/value – *The current case demonstrates that diagnostic overshadowing may occur for autism in the context of early trauma. The case further highlights the importance of not ascribing trauma-related symptoms to autism, as service provision and treatment need to take account of both. Overlooking autism in individuals who have experienced early traumatisation may result in a risk that intervention and care are not appropriately adapted, which may involve a risk of exacerbating trauma symptoms.*

Keywords *Assessment, Autism, Intellectual disability, Post-traumatic stress disorder, Trauma, PTSD*

Paper type *Research paper*

(Information about the authors can be found at the end of this article.)

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Background

- Potentially traumatic experiences and post-traumatic stress disorder appears to be highly prevalent in autistic people (Haruvi-Lamdan et al., 2020; Reuben et al., 2021; Rumball et al., 2021b).
- Autistic individuals appear to be over-represented among individuals experiencing early adversity (Christoffersen, 2022; McDonnell et al., 2019)
- Risk of overlooking PTSD in autistic people, including those with co-occuring intellectual disabilities (Kildahl & Helverschou, 2024; Rumball et al., 2021a, 2024)
- Risk of misdiagnosing autism as borderline personality disorder (BPD) in early adversity, particularly for autistic women? (Kentrou et al., 2024; Rumball et al., 2024)

Background

- Recommended strategies in mental health assessment for people with difficulties in self-reporting (Bakken et al., 2016; Deb et al., 2022; Kildahl et al., 2024) may be less appliccable for individuals with early adversity

Aim/Methods

- Describe and explore assessment strategies used to distinguish between autism and the consequences of early traumatisation in a clinical case
- Case study methodolgy (Yin, 2014)
- Ethics: Data Protection Officer, Oslo University Hospital (#23/24286). Informed, written consent from the patient and her legal guardian, both read and approved the manuscript prior to submission.
- The patient has been anonymised

Patient history

- Rebecca (24)
  - Mild intellectual disability, BPD, PTSD
  - Referred for assessment of ADHD, due to «extreme» impulsivity
  - Self-harm from early childhood, social/communicative difficulties
- History of negligence, parental mental health problems, domestic abuse. Foster care from middle childhood – frequent changes in placements
- Reported sexual abuse by a family member

Current challenges

- Variable day-to-day functioning,
  - Alternating between social withdrawal/isolation,
  - Aggressive outbursts
  - Running away
  - Irritability
  - Repeated questions
  - Attempts to «control» staff behaviour (person-specific strategies)
- Frequent staff turnover, loss of relationships

Assessment

- Hospital-at-home: Clinical psychologist, psychiatrist, experienced intellectual disability and mental health nurses
- Patient history, review of all records from previous assessments, treatment, and follow-up (including child welfare services)
- Assessment tools:
  - WAIS-IV, Vineland-III, BRIEF-A, SCQ, Sensory Profile Checklist
  - Mini PAS-ADD, PAC, ABC,
  - ITQ, LANTS-ID
  - Scale of Emotional Development
- Medical examination and genetic assessment
- Attempted ADOS-2, ADI-R

Information from the patient

- Rebecca had difficulties completing assessment interviews
- Informal interactions and conversation with team members - scored self-report measures based on these conversations (with Rebecca's knowledge)
- She reported emotional instability, suicidal ideation/self-injurious behaviours, feeling empty/numb/helpless/powerless, lack of hope, lack of initiative, nightmares/flashbacks of sexual abuse, occasional freeze responses, difficulties with others making decisions for her

Diagnostic conclusions

- «I want to feel safe, but my body doesn’t know what it means to feel safe»
- Divergence in reports from direct service providers for «challenging» behaviours, not for mental health symptoms
- Autism, mild intellectual disability, complex PTSD
- Rebecca reported to recognise herself as autistic, when learning about autism

Initial treatment

- Establishing a common understanding of Rebecca and her difficulties, including Rebecca and all staff members
- Trauma-informed care (Keesler, 2014; Truesdale et al., 2019)
- Positive results, thus far

Discussion

- Strong focus on early adversity and trauma experiences -> Rebecca's autism had not been recognised, despite social and communicative difficulties from early childhood
- Diagnostic overshadowing, but the «other way»
- Rebecca herself was the only source for information about sexual abuse
- Interactions of PTSD symptoms and autism-related difficulties, e.g., transitions, generalising across personal relationships

Discussion

- The current assessment was comprehensive, but…
  - Rebecca's scores on the trauma checklists were in line with the complex PTSD diagnosis
  - Scores on the ADI-R algorithm and the SCQ, despite the lack of proxy report from a family member, were in line with the autism diagnosis
- Can we trust the assessment tools, even if they have weaknesses?
- Changed diagnostic understanding -> changed attitudes towards Rebecca and changed interpretations of her behaviours

Take-home messages

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Thank you for your attention!

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