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Autism/IDD and Catatonia

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ECHO IDD Complex Behavior

Disclosure: *The speakers have no relationships with any commercial firms having products related to topics discussed today. Actual disclosure forms are available upon request.*

Objectives

- Review what we know about catatonia and autism/IDD
- Review clinical features of catatonia presentation, evaluation, and treatment
- Discuss long-term outcomes in catatonia associated with autism/IDD and future directions

Catatonia in ASD/IDD

- Emerging science and awareness - *prevalence estimates as high as 12-20%*
  - *Higher risk in "syndromic" forms of autism/rare gene disorders?*
  - *Down Syndrome Regression Disorder – may be a form of psychosis/catatonia, or is catatonia a symptom of DSRD?*
- Underlying trigger may be medical/neurologic/psychiatric
  - *Medical/neurologic causes typically present more acutely*
  - *In autism/IDD, onset is often sub-acute/chronic (psychiatric?)*
- Psychosis/thought disorder felt by most autism/IDD experts to more often stem from a primary affective disorder (depression, mania, OCD, PTSD)
- Can present as "hyperkinetic" (difficult to differentiate from "self-stim")
- Consider with **unexplained new onset weight loss, incontinence, and new disruptive behaviors**
- *Anti-psychotic class can sometimes worsen catatonic symptoms*

Hasan S, Hussain I, Chadwick L, et al. J Autism Dev Disord, 2025: https://doi.org/10.1007/s10803-025-06855-3
Smith JR, Lim S, Bindra S, et al. MedRxiv, https://doi.org/10.1101/2024.09.05.24312724.

Catatonia in ASD/IDD – rare gene disorders

A wide range of neurodevelopmental genetic syndromes and rare gene disorders have been associated with **psychosis and/or catatonia**. Two recent systematic reviews identified **47–78 distinct genetic conditions** reported in association with catatonia alone.

Of the chromosomal microdeletion/duplication syndromes, those most commonly associated –

- 22q11.2 deletion syndrome **(DiGeorge/velocardiofacial syndrome)** — The most common and best-studied genetic cause of psychosis; ~25% develop schizophrenia or schizophrenia-like features. Also the second most commonly reported genetic syndrome in catatonia.
Phelan-McDermid syndrome (22q13.3 deletion / SHANK3 mutations) — The most frequently reported genetic condition in catatonia. Also associated with psychosis, bipolar features, and regression, particularly from adolescence onward.
1q21.1 deletion and duplication — Both associated with schizophrenia.
15q11.2 deletion (Burnside-Butler syndrome) — Associated with schizophrenia.
15q13.3 deletion — Strongly associated with schizophrenia and epilepsy.
15q11-q13 duplication (Prader-Willi/Angelman region) — Duplications at this locus carry among the highest risk for ASD and are also associated with psychosis.
16p11.2 deletion and duplication — Both associated with schizophrenia.
3q29 deletion — Associated with a very high risk of schizophrenia.
NRXN1 deletion — Deletions of the neurexin-1 gene are associated with schizophrenia and ASD.
7q11.23 duplication (Williams syndrome region duplication) — Associated with schizophrenia risk.
17q12 deletion – Associated with schizophrenia and ASD.
17p13.3 microduplication - Recently reported in association with recurrent catatonia.

What is catatonia and why is it difficult to diagnose in autism?

- Catatonia is categorized as a sub-type of schizophrenia (DSM-5)
  - Cluster of mood, motor, vocal, and affective symptoms
  - Can be “malignant” and life-threatening with autonomic symptoms (HR, temp, breathing)
  - Pre-frontal/anterior cingulate circuitry implicated
- Prevalence in autism unknown and difficult to recognize
  - Overlap of catatonia symptoms and features of autism
  - Variability in catatonia symptoms from day to day and moment to moment (hyperkinetic and hypokinetic)
  - No biomarkers in majority of cases
  - Onset is often sub-acute/chronic
- Additionally
  - Psychiatric providers unfamiliar with neurodevelopmental disorders
  - Psychiatric evaluators often don’t now the pre-onset baseline

Catatonia in ASD/IDD – Clinical Characteristics

- 6 primary symptoms clusters – *(examples not all inclusive list)*
  - **Psychomotor activity**
    - Freezing AND new onset repetitive/purposeless
  - **Speech disturbances**
    - Mutism AND new echolalia
  - **Change in behavior/skills/function**
    - Loss of self-help skills including toileting, eating/drinking
  - **Mental health symptoms**
    - Aggression/self-injury, agitation/restlessness, loss of interests/social withdrawal
  - **Physiologic symptoms**
    - Sleep/insomnia, fever, increased pupillary size, diaphoresis, incontinence
  - **Symptoms related to arousal and awareness**
    - Thought disturbances

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Catatonia in ASD/IDD – Treatment Considerations

- **Baseline Bush-Francis Catatonia Rating Scale is elevated at baseline** in autism without catatonia
  - Assessment more challenging if the clinician did not know the person prior to catatonia symptom onset
- **Variability** from day to day, hour to hour, can impact the evaluation
  - Videos of observed behaviors outside of clinic can be valuable
- Treatment most effective – **benzodiazepines and ECT**
- **"Lorazepam challenge"** with pre- and post-measurement of symptoms often necessary to confirm dx
  - Inpatient and outpatient protocols ("playbook" of inpatient is to push dose to sedation)
- Treatment with **benzodiazepines often requires very high dose**
  - Challenging for providers and families to accept
- Treatment with ECT on outpatient basis in WA State **requires judge/court approval**
- Long-term outcomes suggest **incomplete recovery** in majority of cases

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Catatonia and Autism/IDD – Long-Term Outcomes and Family Perspective

- Carol Allread, LEND fellow, parent and family advocate

Future Directions

What We Need

- A biomarker beyond just the lorazepam challenge to assist in diagnosis
- Improved early recognition along with studies of the impact of early treatment on long-term outcomes
- Explore both pharmacological and neuromodulatory novel and innovative therapies targeted at treatment early in condition

Resources

[Catatonia in Autism - Family/Caregiver Information Sheet]

[SPACES Webinar Series]

Autism Science Foundation
"Let's talk about catatonia."
Podcast, March 31, 2025
https://asfpodcast.org/archives/1850

The Catatonia Foundation
"Catatonia in autism and other neurodevelopmental disorders."
https://www.thecatatoniafoundation.org/catatonia-in-autism

Questions and Discussion

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