Catatonia

in children with intellectual disability

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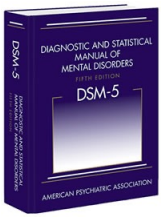
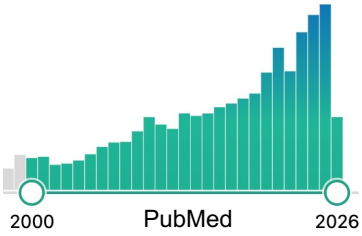
1

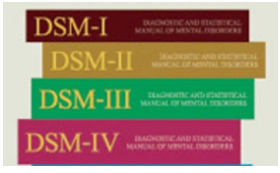
History

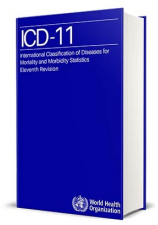
Kahlbaum

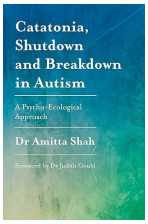
Kraepelin











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Epidemiology

Prevalence estimates in:

- Paediatric psychiatric inpatients 0.6-17% (Benarous et al, 2018)
- Autism 4-17% (Ghaziuddin et al, 2012)
- Phelan-McDermid Syndrome 53% (Kohlenberg et al, 2020)

No good data in ID or children with ID

Catatonia has the highest mortality risk of any paediatric psychiatric diagnosis:

- 20% mortality rate in untreated malignant catatonia (Cornic et al, 2009)

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Risk factors

- **Autistic** (Ghaziuddin et al, 2012) especially if **impaired expressive language and passivity in social interactions** (Wing & Shah, 2006)
- **Intellectual disability** and **being non-verbal** (Breen & Hare, 2017)
- **Adolescent** (Breen & Hare, 2017)
- **Male** to female ratio of 5:1 (Breen & Hare, 2017)

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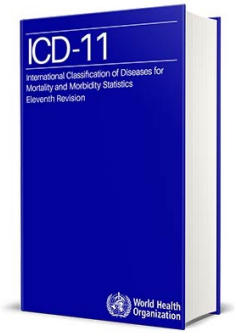
Aetiology of Catatonia in Children with ID



Catatonia (ICD-11):

1. Caused by mental disorder
   - Depression, anxiety, OCD, psychosis, bipolar disorder
   - ASD and/or ID (as opposed to risk factor)

2. Induced by substances or medications
   - Psychotropic medication
   - Anti-seizure medication

3. Secondary syndrome (due to a medical or genetic condition)
   - NMDA encephalitis
   - Any condition worsening (due to communication limitations)

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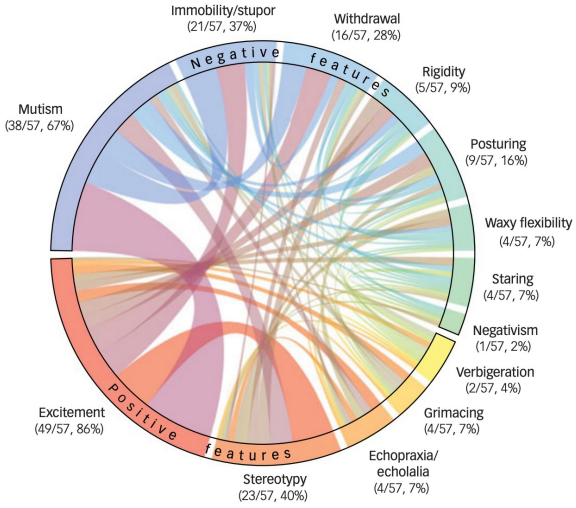
Aetiology of Catatonia in Children with ID



In children with NMDA encephalitis:

- Catatonia was common (86%)
- Symptoms under-recognised
- Immunotherapy was most effective treatment

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Eyre et al, *BJPsych Open* (2020)

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ICD-11 Diagnostic Criteria

Wing and Shah (2000) highlighted substantial overlap of behavioural features shared by autism +/- ID and catatonia

At least 3 symptoms from:

1. Staring
2. Ambitendency
3. Negativism
4. Stupor
5. Mutism

Decreased psychomotor activity

6. Extreme hyperactivity
   or
   Impulsivity
   or
   Combativeness

Increased psychomotor activity

7. Grimacing
8. Mannerisms
9. Posturing
10. Stereotypy
11. Rigidity
12. Echophenomena
13. Verbigeration
14. Waxy flexibility
15. Catalepsy

Abnormal psychomotor activity

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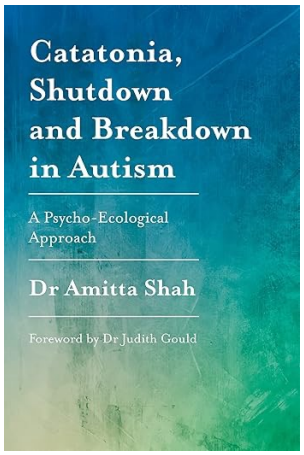
Catatonia in Autism & ID



Appendix 1

Autism Catatonia Evaluation (ACE-S)

Section A – Deterioration (Independence, Speech, Activity)

Section B – Movement Difficulty and Shutdown

Section C – Movement and Behaviour Abnormalities

Section D – Overlapping Catatonia/Autism Features

Section E – Autism Breakdown

Section F – Secondary Difficulties

Described 5 "subtypes" of catatonia in ASD:

1. Chronic catatonia
2. Acute catatonia
3. Catatonia as shutdown
4. Episodic/lifelong catatonia-type difficulties
5. Catatonia features (not diagnostic)

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Catatonia in Autism & ID

Dhossche (2004) proposed that autism may be an early expression of catatonia

Ohta and colleagues (2006) proposed that catatonia in autism be considered an epiphenomenon of autism, or a comorbidity in adolescence or early adulthood. 73% of their sample had prodromal symptoms (gradual emerging sluggishness with compulsive behaviours lasting for more than one year before the manifestation of typical catatonia)

Additional complexities due to neuro-behavioural features of neurogenetic conditions:

- Echo-phenomena in Fragile X
- Episodic regression in Phelan-McDermid Syndrome
- Autonomic instability in Rett syndrome

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Our thoughts (based on limited research & our clinical experience)

Autistic catatonia or shutdown

Intermittent catatonia as part of life-course ID +/- ASD

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Autistic catatonia or shutdown

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- Ohta and colleagues (2006) proposed that catatonia in autism be considered an epiphenomenon of autism. 73% of their sample had prodromal symptoms (gradual emerging sluggishness with compulsive behaviours lasting for more than one year before the manifestation of typical catatonia)

- Case for intermittent catatonia from neurogenetic conditions:
  - Varying echo-phenomena in Fragile X
  - Episodic regression in Phelan-McDermid Syndrome
  - Autonomic instability in Rett syndrome

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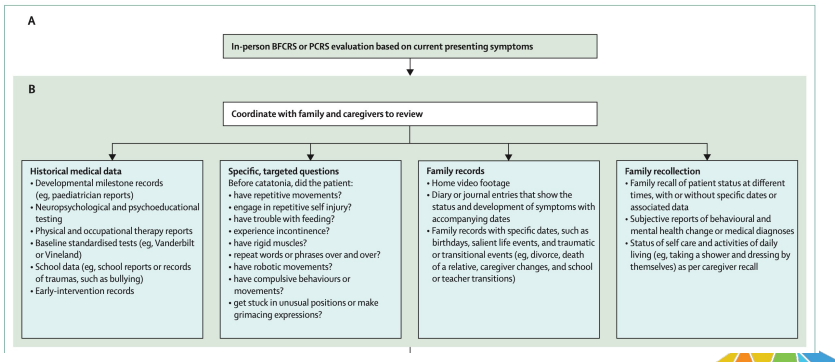
Lancet Psychiatry 2023; 10: 228–34

Catatonia in neurodevelopmental disorders: assessing catatonic deterioration from baseline

Aaron J Hauptman, David Cohen, Dirk Dhossche, Marie Raffin, Lee Wachtel, Vladimir Ferrafiat



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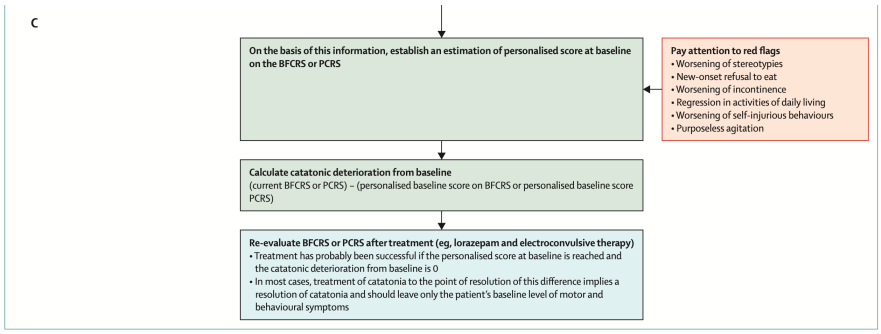

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Our thoughts (based on limited research & our clinical experience)

- But beware symptom overlap
- Note good recent resources:
  1. BAP guidelines (Rogers et al, 2023)
  2. Samsel C et al (2026) Recommendations for a Pediatric Catatonia Clinical Pathway in Acute Medical Care Settings: A Delphi Consensus Study, Journal of the Academy of Consultation-Liaison Psychiatry (pre-proof)

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Pathway Initiation

- Pathway activated when concern for catatonia arises (e.g., classic features, DSM-5-TR criteria) — Factors must persist ≥ 2 weeks in non-urgent cases
- 3+ consensus factors present:
  - behavior change,
  - abnormal movements,
  - autonomic instability,
  - personality /emotional changes
  - cognitive/speech dysfunction
  - decreased consciousness

  — Admission to hospital for comprehensive assessment & treatment

Initial Screening and Assessment

Ensure meets DSM-5-TR criteria for catatonia	Scales at every visit (ambulatory) or daily (hospital), esp. pre/post interventions
Bush-Francis or Pediatric Catatonia Rating Scale (routine)	Use pediatric delirium scale in critical care settings
One positive pediatric catatonia screen → workup	Scales inform diagnosis, progression, assess progress, guide treatment

Diagnostic Evaluation

Routine labs: CMP, UDS, TSH, CBC, CRP, CK, ANA, ESR, B12/Folate, thyroid antibodies, iron, autoimmune panels	Imaging: EEG, MRI brain (depending on circumstance), pelvic ultrasound, EKG
CSF studies (if indicated): encephalitis and encephalopathy panels, cell counts, oligoclonal bands, IgG index, cultures	Consider Differential Diagnosis: psychotic disorder, autoimmune encephalitis, delirium, drug-induced, ASD, MDD, bipolar, tumors, NMS, SLE, hepatic encephalopathy, epilepsy

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Continuing Care Delivery and Monitoring

Daily psychiatry follow-up (stable & unstable patients) and pediatric neurology to evaluate all patients	Safe transfer to psychiatry: stable nutrition, vitals, BERT/security, crash cart, seclusion/restraints, overnight provider support
Essential daily care: nutrition, hygiene, safety, physical exams, bowel regimen	Medically unstable → manage on medical services
Supportive care: ulcer prevention, fall precautions, OT/PT/SLP, Child Life, eye drops, labs	Transfer to critical care if: severe instability, seizures, fever, rigidity, renal failure
Transfer/discharge if: ambulating, seizure-free >48h, labs normalized, enteral nutrition	

Management: PART 1 - Lorazepam

First Line Treatment: Lorazepam	IV administered as fast or slow push
Lorazepam route of administration dependent on clinical situation: IV preferred	Weight based dosing for children <12 years old
Reassessment within 60 min	Repeat dose if no effect within 30-60 min
PO prioritized for: lack of IV access, prior benefit, anxiety with IV/IM, intolerance, mild presentation, least invasive route	IM prioritized for: prior benefit, imminent risk, oral aversion, severity, decompensation
IV prioritized for: available access, oral aversion, imminent risk/severity, prior benefit, rapid decompensation.	Maximum daily dose dependent on side effects and ECT availability
No maximum daily dose when ECT not available	

Management: PART 2 - ECT and Other Treatment

ECT is best next step when there is limited/no response to lorazepam	Memantine or Amantadine may be used adjunctively
Should be pursued after parital/no response to optimized lorazepam regardless of accessibility	Low potency antipsychotics for mania/psychosis in stable patients - Quetiapine preferred
Emergent ECT Criteria: severe autonomic instability, end organ failure, severe rigidity, unconsciousness requiring sedation, inability to maintain oral intake/hydration >72 hours	Antipsychotics may be considered in mixed presentations

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Assessment - When to suspect Catatonia?

- A spectrum starting with an increase in anxiety on one end and classical motor catatonic state on the other end.
- Brief episodic vs more sustained
- Hesitancy before daily tasks and transition
- Increased indecisiveness / decision paralysis
- Increase in repetitive/ stereotyped / compulsive behaviours
- Verbigeration
- Mutism or increased vocal stereotypies
- Significant / prolonged initiation difficulties
- Stuck fixed postures

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Assessment

- **History and timeline**
- Was there a trigger?
- Any regression?
- Sudden onset vs insidious

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History

- In our clinical sample of 25 young people with Catatonia, we found that all had at least one additional psychiatric diagnosis pre-dating the onset of catatonia, anxiety disorder being the most prevalent, followed by OCD and depressive disorder.
- Clinical studies also found high prevalence of co-morbid psychiatric disorders, particularly mood related (Wing & Shah, 2006)

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Assessment

- History and timeline
- **Was there a trigger?**
- **Any regression?**
- **Sudden onset vs insidious**

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Assessment

- Examination
- Investigations

21

Treatment approaches

- Is there an identified psychological trigger or medical cause?
- Medications
- Non-medication approaches
- ECT

22

Treatment: medications

- Lorazepam
- SSRIs
- Anti-psychotic medication

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Treatment: non-medication strategies

- Verbal prompts
- Physical nudge
- Modelling
- Mirror-ing
- Other strategies

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Treatment: long term

- Treating anxiety / therapies
- Environmental modifications

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