**AXIS III: Cracking The Code**

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**Biological Factors**

- 5-HIAA in cerebrospinal fluid (Serotonin: Lexapro, Prozac, Zoloft, etc)
- B-blockers (Propranolol, Inderal, etc)
- Norepinephrine (Cymbalta, Effexor XR, etc)

**Medical/Neurological Conditions**

- 85% have untreated, under-treated or undiagnosed problems
- Worsened by restrictions on care (labs, office visit frequency and length)
- Medications used in ways they were never intended, in unsafe ways, with abbreviated monitoring protocols

**Bio-Psycho-Social Developmental Formulation**

- GABA may have inhibitory effect on aggression (Ativan, Klonopin, Valium, etc)
- Pre-frontal or frontal functioning
- Dysfunction in temporal lobe activity

**Common Causes of Behavioral Changes**

- Pain (emotional and physical)
- Medication side effects/undiagnosed or under-treated medical conditions
- Sleep disorders
- Psychiatric illnesses, including the effects of trauma
Rule out Medical Issues First

- Organic
- Organic
- Organic
- Then psychiatric...

Medical Assessment

Laboratory workup:
- CBC/differential
- Glucose
- Kidney/Liver/Thyroid
- Syphilis serology
- HIV antibody/Hepatitis screen
- Pregnancy test (beta HCG)
- Vitamin B12/folate levels/Thiamine level
- RF/ANA
- EEG, CT/MRI, etc

Polypharmacy

- Avoid using two medications from the same therapeutic class at the same time
  - Intraclass polypharmacy (e.g., two SSRIs)
- Using two or more medications from different therapeutic classes at the same time (interclass polypharmacy) may be appropriate and needed in certain situations (e.g., psychotic or bipolar depression, partial response to one drug, comorbid conditions)

Other Medication Practices to Avoid

- Long-term use of benzodiazepine antianxiety agents (e.g., diazepam) or shorter acting sedative hypnotics (e.g., zolpidem)
- Use of long-acting sedative hypnotics (e.g., chloral hydrate)
- Use of anticholinergics without extrapyramidal symptoms
- Higher than usual doses of psychotropic medications
- Use of phenytoin, phenobarbital, primidone as psychotropics
- Long-term use of PRN medication orders
- Failure to integrate medication with psychosocial interventions

A Distinguished Group

- “Antipsychotics are the most widely prescribed medications in individuals with intellectual disability even if schizophrenia and other psychotic disorders do not affect more than 3% of such population”

Antipsychotics in ID

- They are often utilized for their general tranquilizing effect rather than their specific therapeutic purpose
- “Antipsychotic drugs are often incorrectly used to manage or prevent all kind of behavioural problems or undiagnosed symptomatological clusters”
Assessing for Psychosis
• Remember it is less common than we think
• Use your observational skills
• Take your time
• Always consider trauma, medication side effects and medical conditions

Usually NOT Psychosis
• Self-injury
• Explosive aggression
• Phenomena the person can stop or start at will
• Self talk

Down Syndrome
• Hearing impairment (65-89%)
• Respiratory system (upper and lower)
• Joint and muscle disorders (including atlantoaxial instability in up to 20%)
• Cardiac conditions (30-45%)
• Celiac disease (10%)
• Hypothyroidism
• May not mount fever
• Shortened life expectancy

Diane
• Self injury for the past 30 years
• Increase in SIB in a cyclic pattern, including but not limited to menstrual cycle
• Zoloft, Propranolol, Risperdal 0.25 BID, Clonidine at bedtime

Head Banging
• This is not “normal” for anyone
• TRAUMA/DEPRESSION/ANXIETY
• Headache
• Dental
• Seizure
• Otitis/Mastoiditis
• Sinus problems
• Tinea capitus
• Ryan, 2003

Autism
• Nutritional deficiencies due to being particular about eating only certain foods
• Dental problems due to stereotyped movements or bruxism
• Insomnia (44%-83%)
• Self-injurious behavior
• Seizures (22% to 30%)
Tina

- Knee pain; headaches; left eye pain; job loss
- Geodon; Celexa
- Anxiety evident; start buspirone and rule out medical problems

Fragile X Syndrome

- Seizure disorders (14-20%)
- Joint laxity, flat feet, endocrine disorders, scoliosis
- Macro-orchidism (enlarged testicles)
- Respiratory infection (esp otitis media)
- Mitral valve prolapse (50%)
- Fragile X Tremor-Ataxia Syndrome (FXTAS)
- Females: 16-19% premature ovarian failure (as early as mid 20s)

Primary Care/Preventive Care

- Atypical presentations, behavioral and communication difficulties
- Increased incidence of medical conditions of every organ system
- Physician evaluation of patient with ID is similar to that of an patient with memory loss or delirium
- Detective work, emphasis on observation, interpretation of behavioral presentations

Primary Care/Preventive Care

- United States Preventive Services Task Force, 2007
- Considered evidence based practices
- Accepted as standard of care

Biology of Patients with ID

- Polypharmacy
- Autism: increased vulnerability to ataxia with benzodiazepines
- EPS (movement disorders): increased prevalence if muscular disorders
- Benzodiazepines (paradoxical, disinhibition, memory loss)
- Caution with medications affecting seizure threshold (bupropion, clozapine, other antipsychotics, etc)

Christopher

- “Behavioral changes”
- Bruising, fatigue, “anxious”
- Altered mental status/confusion
- Pancytopenia (decreased red/white blood cells and platelets)
- Depakote probable etiology (prescribed by neurology)
Dave

• Aggression for past 3 months
• Leukocytosis (increased white blood cell count) on lab draw
• Clozapine 200mg at bedtime
• Depakote 500mg twice daily
• Presents in the fetal position

Cardiovascular/Metabolic Issues

- Clearly higher risk in the ID population
- PCP less likely to recommend preventive or maintenance care for patients with ID
- Identified risk for less expected life among patients with MI; for those with MI/ID even more significant

Cardiovascular/Metabolic Issues

- Lack of subjective data
- Increased vulnerability to both metabolic SE and EPS
- The latter can potentiate the former

Cardiovascular/Metabolic Issues

- Stanish et al 2006
- Physical activity 30 minutes moderate activity on most if not all days of the week and/or 10,000 steps daily
- Only 17.55 to 33% of persons with ID met criteria

Cardiovascular/Metabolic Issues

- Fleming et al 2008
- Higher rates of obesity were related to: female gender, elderly, residential placement, Down syndrome
- Mild ID >> Severe/profound ID

Cardiovascular/Metabolic Issues

- Fleming et al 2008
  - Reasons for higher risk:
    - Limited or no ability to understand typical methods for info dissemination
    - Limited or absent opportunities to participate in social activities
    - Lack of trained staff/caregivers
    - Overprotective parents/caregivers
  - Exercise programs: when diet and exercise were combined with behavioral interventions, better results in a study of patients with DS
Sudden sitting down
- Also called “sit down strikes”
- Heart problems
- Syncope/orthostasis/medication SE
- Vertigo
- Otitis (ear infections)
- Atlantoaxial subluxation
- Seizures
- TRAUMA/panic

Cardiovascular/Metabolic Issues
Smoking
Limited data on the ID population
Lower rates among severe/profound ID versus mild ID
Much more likely to quit if discussed with their physician
Increased SMOKING may decrease blood levels of antipsychotic medications

Respiratory System
- Common respiratory conditions over-represented
- Toder et al (2000) those with cerebral palsy and/or TBI are at highest risk
- Poor airway clearance>>pneumonia, apnea

Gastrointestinal System
- More common in those with CP, spina bifida, inborn errors of metabolism
  - GERD (gastro-esophageal reflux disease) is very common
  - GERD in institutional populations: 50% in those with IQ < 50 (Bohmer et al 2000)
  - Recommendation: physicians should have low threshold for use of proton pump inhibitors
    (decreases stomach acid produced)

Gastrointestinal Conditions
- Upper GI bleeding: likely GERD
- Complicated by increased threshold to pain, decreased communication ability
- Male gender and history of pica are highest risk for acute abdomen
- H pylori: Type I carcinogen; 2X prevalence of general population

Fist Jammed in Mouth
- Gastroesophageal Reflux Disease (GERD)
- Also: eruption of teeth, asthma, rumination, nausea, anxiety, painful hands, gout
Biting side of hand

- Sinus problems
- Eustachian tubes/ear problems
- Eruption of wisdom teeth
- Dental problems
- Pain or paresthesia in hands

Matthew

- Laboratory workup
- Consider cbc/diff, BMP and ESR q.2-3 months given medical history (dental abscess) and level of expressive language skills (may facilitate early identification of left shift, abnormal renal function, etc). Rule out common medical conditions including H. Pylori
- Antidepressants/antianxiety: May consider Remeron/Saffol to improve sleep pattern, increase appetite, decrease OCD symptoms and eliminate pill form of venlafaxine which is being metabolized incompletely.
- Antipsychotic: Consider Zyprexa/Zydis as temporary replacement to create consistent antipsychotic therapeutic level, eliminate pill form, potential to increase appetite, improve sleep pattern and reduce OCD symptoms.
- Consider consult with allergist as exacerbating factor in nausea given history sinusitis, multiple environmental allergies and strong family history.
- Rule out lactose intolerance; patient's aunt developed condition in her thirties.
- Consider neurology input if gait instability is not connected to hydration/nutrition status.
- Benzodiazepines may be considered to reduce anxiety; this medication class has been utilized prior to medical procedures per mom with no paradoxical reaction.
- A behavior support plan and behavioral therapy have the most scientific support if no medical etiology ascertained. Core etiologies should be ruled out including: attention seeking, avoidant/stubborn, sensory feedback (provide alternative), oral stimulus if induced vomiting (may be replaced with alternate safe oral stimulus).
- Individual psychotherapy and Group psychotherapy may be considered.

Biting thumb or object with front teeth

- Sinus problems (also the most common reason for thumb sucking and bruxism)
- Eustachian tube and ear problems
- Finger pain/paresthesias
- Gout

Intense rocking

- Not “normal” for patients with ID
- Visceral pain
- Depression
- Anxiety
- Medication side effects

Jill

- “My stomach hurts”
- “I just want to get out of here alive”
- Recent move to new facility
- Cholecystectomy (gall bladder removal)
- Four GI medications
- Hypothyroidism

Menstrual Related Conditions

Breast and cervical cancer screening are arguably the most significant inequality.

Havercamp et al 2004: 11.5% women never had a GYN visit; 26.8% aged over 40 years had no documented mammogram (not D/T low compliance)
Menstrual Related Conditions

- Dizon et al (2005) 90% caregivers approach physicians for menstrual suppression (40% of the time prior to menarche)
- Primary stated concern was hygiene/‘trouble coping’ as opposed to birth control

- Menstrual Related Conditions
  - No identified standard or consensus on how to meet the needs of individuals with ID
  - Depo-provera most commonly prescribed for menstrual suppression
  - Mean age of menarche = 12.13 years (slightly later in CP)
  - Extra caution with IUDs

Menstrual Related Conditions

- Studied SIB, aggression, etc
- NSAIDs effective for 65%
- OCP effective for 40%
- Depo-provera effective in 66%
- There should be a high index of suspicion for painful dysmenorrhea in behavioral presentations

- Odd unpleasurable masturbation
  - Prostatitis
  - Urinary tract or genital infection
  - Rectal injury or infection
  - Parasitic infection
  - Old conditions... (syphilis...)
  - Repetition phenomena (past abuse)
  - Never learned pleasurable masturbation

Cancer

- Colon CA: approximately the same prevalence; other GI cancers more prevalent
- Breast CA: slightly lower; parity and breast feeding impact prevalence
- Cervical CA: related to # partners/frequency of sexual activity
- Prostate: lower prevalence rates shown in 2 studies; recommend same screening until more data

- Muskulo-skeletal System
  - OSTEOPOROSIS:
    - Increased prevalence shown, not limited to post menopausal women
    - Risk factors: Caucasian, inactivity, long term anticonvulsant use, low vitamin D levels, 7Down syndrome
  - Overall rate 17.1% osteoporosis 51% osteopenia
<table>
<thead>
<tr>
<th>Refuses to sit evenly, or at all</th>
<th>Walking on toes</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Hip pain</td>
<td>• Arthritis in the hips, ankles, or knees</td>
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<tr>
<td>• Genital or rectal discomfort</td>
<td>• Sensory integration issues</td>
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<tr>
<td>• EPS (akathisia)</td>
<td>• Tight heel cords</td>
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<tr>
<td>• Clue to ongoing abuse</td>
<td>• Proprioception</td>
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<tr>
<td>• Clue to past abuse</td>
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<thead>
<tr>
<th>Won’t sit</th>
<th>Whipping head forward</th>
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<tr>
<td>• Akathisia</td>
<td>• Atlantoaxial subluxation (at risk are those with Down Syndrome and other syndromes that produce joint laxity)</td>
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<tr>
<td>• Anxiety</td>
<td>• Dental problems</td>
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<tr>
<td>• Depression</td>
<td>• Headaches</td>
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<td>• Back pain</td>
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<tr>
<td>• Other pain</td>
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<tr>
<td>• Sleep deprivation</td>
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<table>
<thead>
<tr>
<th>Waving fingers in front of eyes</th>
<th>Jeff</th>
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<tr>
<td>• Migraine</td>
<td>• Agitation, aggression, refusal to attend day programming</td>
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<tr>
<td>• Corneal scarring</td>
<td>• Visibly in pain at intake appointment</td>
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<tr>
<td>• Cataract</td>
<td>• MRI/X ray series of hip bilaterally and lumbar spine</td>
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<tr>
<td>• Seizures</td>
<td>• Risperdal and low dose Klonopin</td>
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<tr>
<td>• Glaucoma</td>
<td>• No medication on weekends</td>
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<td>• Medication side effects (diplopia..)</td>
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*Ryan, 2003*
CLINICAL PEARLS: Biological

- Weight loss and gain
- Hydration/nutritional status
- Cigarettes
- LABS: request that blood work is ordered
- Increase seizure medications may decrease psychiatric medications
- Rule out PAIN
- PCP/Preventive Care
- Headaches
- Sensory deficits
- Half life and timing of medications/liquid/IM/pill

CLINICAL PEARLS: Psychological

- Psychotherapy (Individual and/or Group)
- Trauma history
- Document life story
- Are this individual’s psychological needs being met?

CLINICAL PEARLS: Social

- Communicative Ability: iPads, communication boards, etc
- Sensory Evaluation
- Ensure all environments are safe, consistent and attend to individual’s sensory needs
- Community engagement

CLINICAL PEARLS: Developmental

- Increase knowledge of developmental stages (cognitive strengths, communicative ability, syndromal information, etc)
- How does this individual perceive and interpret the world?
- If trauma history, at what developmental stage(s) did this occur?

Conclusion

- Significantly higher risk of medical, genetic, neurological and psychiatric conditions
- Every organ system is at greater risk
- The MH clinician/advocate plays a vital role in facilitating access to interdisciplinary team members

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