Pharmacological and Non-pharmacological Interventions for Challenging Behaviors in Persons with Intellectual and Developmental Disabilities (IDD): A Rational Approach for Community Mental Health Providers

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Presentation Outline

- Challenging behaviors: Introduction, definition, prevalence, & need for treatment
- Pharmacological approaches to aggressive behavior
- Non-pharmacological approaches to aggressive behavior
- Treatment approaches to self-injurious behavior
- Treatment approaches to sexualized challenging behavior
- Summary, conclusions, Q&A

Defining Challenging Behavior

Socially unacceptable behaviour that causes distress, harm or disadvantage to the person themselves, or to other people (or property), and usually requires some intervention (Deb et al., 2006).

Culturally abnormal behavior of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behavior which is likely to seriously limit the use of – or result in the person being denied access to – ordinary community facilities (Emerson, 2001).

Challenging Behaviors in the Clinic

- Physical and verbal aggression towards other people
- Physical harm and damage to property
- Self-harm and self-mutilation
- Severe hyperactivity and stereotypical movements
- Sexualized challenging behaviors

Challenging Behaviors & Psychopathology

- Challenging behaviors may be a symptom or manifestation of any number of different psychiatric disorders
- In many cases arriving at a confident psychiatric diagnosis is difficult or not possible
- Accurate psychiatric diagnosis in persons with ID can be very difficult

Treating Diseases vs. Treating Symptoms

Unfortunately, the state of current practice with many persons with ID and behavioral or emotional difficulties today is often that of **symptomatic treatment alone**, in the absence of a reliably-identified psychiatric illness.

Challenging Behaviors & Use of Psychotropic Medications

- Norwegian community survey of psychotropic medication use in the ID population revealed only 27% of those taking medications had a psychiatric diagnosis (Baasland & Engedal, 2009)
- In UK-based survey, 47% of patients with challenging behaviors were taking antipsychotics, but only 12% of those patients had a diagnosed mental illness (Sheehan et al., 2015)

Challenging Behaviors & Use of Psychotropic Medications

Compared to adults with ID who do not display challenging behaviors:

Those with challenging behaviors are ~ 2x as likely to be prescribed any psychotropic medication

And ~ 3x as likely to be prescribed an antipsychotic

(Bowring, et al., 2017)

Approach to Management of Challenging Behaviors with Psychotropic Medications

- 2009 World Psychiatric Association international consensus guidelines
- Recognition that treatment is still needed to help manage behaviors even in the absence of a confident psychiatric diagnosis

(Deb et al., 2009)

WPA Guidelines

Assessment & formulation:

- **Multidisciplinary input with input from the patient**
- Formulation **must** be attempted even in the absence of a clear medical/physical or psychiatric diagnosis

WPA Guidelines

When to consider medication:

If NO identifiable or treatable physical/psychiatric disorder can be identified, then non-medication interventions should be tried first

WPA Guidelines

When to consider medication:

- Failure of non-medication based interventions
- Risk/evidence of harm/distress to self, others, or property
- High frequency/severity of challenging behavior
- To treat an underlying psychiatric disorder
- To enable implementation of non medication-based interventions
- If individual's placement is at risk

Pharmacological Approaches to Aggressive Behavior

Stephen Ruedrich, MD

Pharmacological approaches to aggressive behavior

"Challenging Behavior" (CB) in persons with IDD is usually a PC way of describing aggression: aggression directed at others, at self (SIB), or at property

Most studies of CB treatment, both pharm. and non-pharm., combine CB into a single entity; few separate aggression to others from SIB

Most studies are not methodologically-sound, not prospective, with little use of blinding or placebo-controls, random assignment, or use of standardized outcome measures

Pharmacological approaches to aggressive behavior

Medications for aggressive behavior in persons with IDD are believed to have been:

Excessively prescribed

Less effective than hoped for

Inadequately monitored

Resulted in side effects which should limit use

Pharmacological approaches to aggressive behavior

What is the evidence for these beliefs?

Pharmacological approaches to aggressive behavior

Note:

Most of the negative feedback about use of medications to treat CB is directed at antipsychotics

This class of medications has been the most frequently utilized, and have the most serious side effect profile

Pharmacological approaches to aggressive behavior

Large study in UK, using total population sampling,
to examine relationship between CB and use of psychotropics:

70% of adults with IDD were taking medication

38% were taking psychotropics

22% were taking antipsychotics

Polypharmacy and high doses were common

Significant association between psychotropic use and psychiatric diagnosis, CB, older age, and male gender

(Bowring et al., 2017)

Pharmacological approaches to aggressive behavior

Adverse Events (AE) in persons with IDD treated with psychotropics

Study of 103 patients with IDD and CB treated with psychotropics, noting the strength of association between AE and IDD Quality of Life.

84% had at least 1 AE

45% had > 3 AE

61% of those taking > 2 psychotropics had > 3 AE, compared to 13% w/o psychotropics

Having AE had significant negative influence on QOL.

(Scheifes et al., 2016)

Pharmacological approaches to aggressive behavior

Cohort study of 571 general practices in UK, totaling 33K adults with IDD

21% had record of mental illness (MI)
25% had record of CB
49% had record of taking psychotropic medications

During f/u:
Rate of new CB was ~ new cases of mental illness
Rate of new psychotropic use was about twice either CB or MI
Rate of new antipsychotic prescribing significantly higher in those with CB

Conclusion: % of people with IDD treated with psychotropic drugs far exceeds % with MI, and antipsychotics are often prescribed for CB

(Sheehan et al., 2015)

Pharmacological approaches to aggressive behavior

Meta-analysis of psychotropic treatment of CB in children with IDD

Fourteen studies, totaling 912 participants available for meta-analysis

Antipsychotics reduced CB in children in short term, to a significant degree (risperidone and aripiprazole)

However, significant side effects, (elevated prolactin and weight gain)

Evidence inconclusive for effectiveness of AED and antioxidants for CB

Quality of evidence was low, and no long term f/u studies

(McQuire et al., 2015)

Pharmacological approaches to aggressive behavior

Dutch study, comparing two antipsychotic discontinuation schedules

- Multicenter parallel group design of 98 adults with IDD
- Antipsychotics were all prescribed for CB, for > 1 year
- Tapered by 12.5% every 2 or 4 weeks to discontinuation
- F/U 12 weeks after discontinuation
- Discontinuation stopped for significant worsening of CB
- Primary outcome measure was the Aberrant Behavior Checklist (ABC)

(de Kuijper et al., 2014)

Pharmacological approaches to aggressive behavior

Dutch study, comparing two antipsychotic discontinuation schedules (cont.)

- 43/98 achieved complete discontinuation
- 7/98 resumed use of antipsychotics
- ABC improved significantly for those who discontinued
- No change between slower and faster discontinuation
- Higher rates of EPS and autonomic symptoms at baseline was associated with less improvement at discontinuation
- Higher ABC at baseline predicted incomplete discontinuation

(de Kuijper et al., 2014)

Pharmacological approaches to aggressive behavior

NY study of 4069 adults with IDD (including ASD)

58% took one or more psychotropics
- 45% took an antipsychotic
- 23% took an antidepressant
- 19% took a mood stabilizer
- 16% took an anti-anxiety agents

50% of psychotropics were for treatment of psychiatric illness
13% for CB
38% for both

Conclusion: Majority of psychotropics were for illness, not aggression

(Tsiouris et al., 2013)

Pharmacological approaches to aggressive behavior

Dutch study of 3300 patients
- Prevalence of use of antipsychotics was 30%
- 5% for chronic psychotic disorder
- 25% for non-schizophrenic psychotic disorder
- 69% for challenging behavior

Prescribers were willing to discontinue antipsychotics in about 50% of patients, more so those prescribed for challenging behavior.

Reasons for not stopping:
- Motor restlessness
- ASD
- Discontinuation previously unsuccessful
- Objections of guardians

(de Kuijper & Hoekstra, 2017)

Pharmacological approaches to aggressive behavior

DB-PC trial in 86 non-psychotic patients with aggressive CB

- 10 Centers in UK and Australia
- Random assignment haloperidol (n=28); risperidone (n=29); placebo (n=29)
- Assessed at 4, 12, and 26 weeks
- Primary outcome was change in CB after 4 weeks, using MOAS

Results:

- 80% had 80% adherence
- Aggression decreased substantially in all three groups, with placebo group showing the greatest change
- No significant difference in AE
- At no time did placebo show worse response than antipsychotics

Conclusion: Antipsychotic drugs should no longer be regarded as acceptable routine treatment for CB in person with IDD

(Tyrer et al., 2008)

Pharmacological approaches to aggressive behavior

Rebuttal to Tyrer et al., Lancet 2008:

- "Absence of evidence is not evidence of absence"
- Sampling error (subjects qualified if they had had 2 aggressive episodes and MOAS score of 4 in week before inclusion; may not have shown repetitive or continuing aggression without other explanation)
- Poor randomization (risperidone group had greater severity at baseline)
- Inadequate duration of treatment (antipsychotics work better over time, placebo response fades; week 12 change scores for active drugs were double that of placebo)
- Inadequate power (recruitment fell short of power calculations needed)

(Tierney & Arnold, 2008)

Pharmacological approaches to aggressive behavior

In **2007**, the **Journal of Intellectual Disability Research** (**JIDR**) published a series of papers which reviewed the main classes of psychotropic **medications** re their **efficacy for behavioral problems** in persons with ID

"The effectiveness of (**fill in drug class here**) in the management of behaviour problems in adults with intellectual disability: A systematic review

(Deb et al., 2008)

Pharmacological approaches to aggressive behavior

Orienting Slide:

When the Food and Drug Administration approves a new drug for a particular clinical indication, how many subjects (patients) must have been studied?

Pharmacological approaches to aggressive behavior

FDA-approved antipsychotics; numbers of patients reported, in double-blind, placebo-controlled trials:

Risperidone (Risperdal)

160+513+1356+246+365 = 2640

Olanzapine (Zyprexa)

149+ 253+326 = 728

Ziprasidone (Geodon)

139+302+419+200+294 = 1354

Pharmacological approaches to aggressive behavior

JIDR REVIEW: MOOD STABILIZERS in ID

Only 7 studies were found:

Two controlled trials of lithium	(N=74)
One controlled trial of carbamazepine	(N=10)
One retrospective case series with lithium	(N=66)
One prospective case series with valproate	(N=28)
One retrospective case series with valproate	(N=28)
One retrospective case series with topiramate	(N=22)

Conclusion:

"Some" support for the use of **mood stabilizers** for mgmt of **behavioral problems in adults** with ID."

"However, because of methodological difficulties,…. **interpret with caution."**

Pharmacological approaches to aggressive behavior

JIDR REVIEW: ANTIDEPRESSANTS in ID

10 studies were found:

One randomized controlled trial of clomipramine	(N=10)
Two cohort studies of fluoxetine	(N=35)
Two open trials of fluoxetine	(N=30)
Two prospective case series of fluvoxamine	(N=74)
One prospective case series of paroxetine	(N=15)
One retrospective uncontrolled study of paroxetine	(N=14)
One retrospective uncontrolled trial of both paroxetine and fluoxetine	(N=33)

Conclusion:

"**Existing evidence** on the use of **antidepressants** for the management of behaviour problems in adults with ID is **scant**"

The small clomipramine trial was positive

"**Responses to SSRIs were varied**,…**some clearly favourable**,….**some negative**….**some both** positive and negative outcomes."

Pharmacological approaches to aggressive behavior

JIDR REVIEW: ANTIPSYCHOTICS in ID

9 studies were found:

One randomized controlled trial of risperidone	(N=39)
Two prospective case series of risperidone	(N=50)
One prospective case series of quetiapine	(N=15)
One prospective case series with fluphenazine	(N=12)
One case crossover series with zuclopentixol & haloperidol	(N=34)
Two retrospective case series with clozapine	(N=41)
One retrospective case series with olanzapine	(N=20)

Conclusion:

"The evidence available at present for the **effectiveness of antipsychotic** medication in the management of **behaviour problems** among ***adults*** with ID is primarily **based on case series**.

For ***adults***, only two RCTs (one includes children) are available.

There are at least **four good quality RCTs involving children** with ID **w/wo autism**, showing **effectiveness of risperidone**."

Non-Pharmacological Approaches to Managing Aggressive Behavior

Jennifer Bellegarde, MS, DO

Outline

- Understanding the Concept of Challenging Behavior
- Causes of Challenging Behavior
- Assessment Strategies
- Interventions
- Case Vignette
- Small Group Discussion

Challenging Behavior…

- is not random
- has a reason for happening
- is meaningful
- serves a purpose
- is the expression of an unmet need or want
- can be viewed as a form of communication

The Function of Challenging Behavior

When presented with a patient with challenging behaviors, keep in mind

- People do the best they can, with the skills they have, within a specific context, at a specific time and place

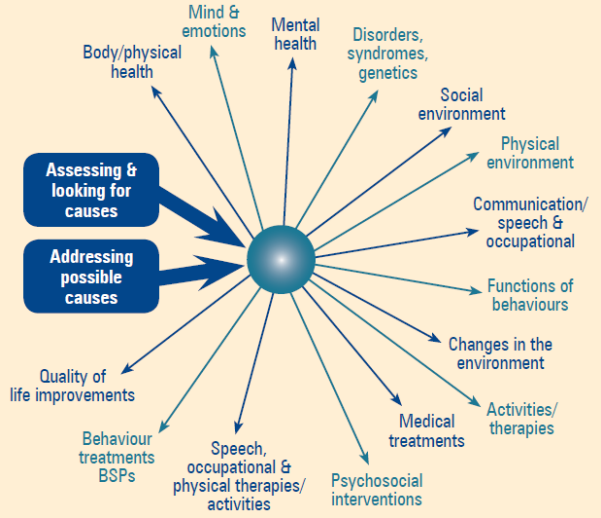
Video Clip

- Understanding Challenging Behavior
  https://www.challengingbehaviour.org.uk/information/information-sheets-and-dvds/positive-behaviour-support.html

Things to Consider when Evaluating a Patient with Challenging Behaviors

- Physical and Medical Concerns
- Mental Health Concerns
- Medication Side Effects
- Communication Issues
- Sensory Issues
- Psychosocial Concerns

The Bio-Psycho-Social Model



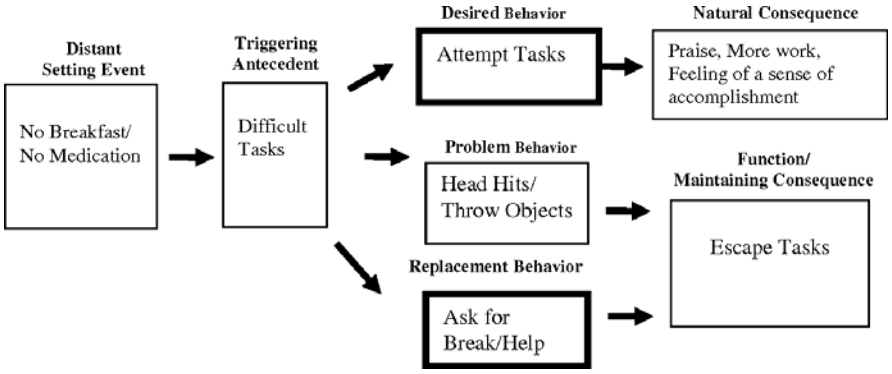
Causes of Challenging Behaviors

PHYSIOLOGICAL	ENVIRONMENTAL	PSYCHOLOGICAL	SOCIAL
Allergies	Air quality	Anxiety	Being stared at
Arthritis	Close proximity to others	Assertiveness	Change in staff
Attention deficit	Humidity	Attitudes	Criticism
Constipation	Lighting	Beliefs	Danger
Delusions	Limited physical space	Boredom	Demands
Dementia	Noise	Dominance	Disapproval
Ear aches	Smells	Fear	Disruption
Energy – too much	Temperature	How thoughts are processed	Frequent change
Energy – too little	Uncomfortable furniture	Loneliness	Lack of social attention
Fractures		Phobias	Not having choices
Headaches		Personality traits	Presence of specific person(s)
Hallucinations		Sex drive	Relocation
Hunger		Shyness	Sexual provocation
Hyperactivity		Submissiveness	Teasing by others
Itching		Suspiciousness	Tone of voice
Medication reactions		Vengeance	Too little to do
Medication side effects		Worry	Too much to do
Pain			
Premenstrual syndrome			
Seizures			
Sex drive			
Thirst			
Tobacco craving			

Assessment Strategies

Learn the ABC's

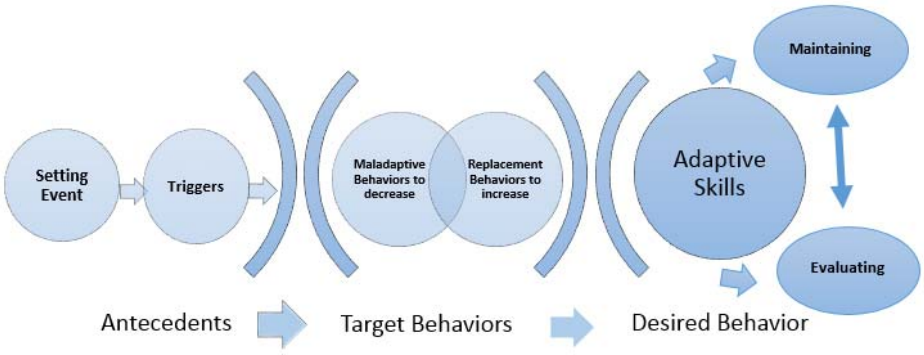
Antecedent → Behavior → Consequence



Non-Pharmacological Interventions

- Social Interventions
- Behavioral Therapies
- Positive Behavioral Support
- Prevention Strategies
- Replacement Behaviors
- Cognitive Behavioral Therapy (CBT)
- Mindfulness
- Technology-Assisted Interventions

Sample Case


Maintaining
Setting Event
Triggers
Maladaptive Behaviors to decrease
Replacement Behaviors to increase
Adaptive Skills
Evaluating
Antecedents
Target Behaviors
Desired Behavior

Case Vignette & Discussion

Treatment Approaches to Management of Self-Injurious Behaviors (SIB)

Ovayoza Adeleye, MD

OBJECTIVES

- APPROACH TO EVALUATION OF SIB IN THE ID POPULATION.
- EVIDENCED BASED TREATMENT ALGORITHIMS INCLUDING NON- PHARMACOLOGIC AND PHARMACOLOGICAL TREATMENTS.

SELF-INJURIOUS BEHAVIOR

INTENTIONAL DIRECT INJURY OF BODY TISSUE WITHOUT SUICIDAL INTENT.

- HEAD BANGING
- SKIN PICKING
- SCRATCHING
- SLAPPING
- HITTING SELF
- BITING
- EYE GOUGING
- OTHERS

CONDITIONS ASSOCIATED WITH SIB IN IDD

- AUTISM SPECTRUM DISORDER
- GENETIC SYNDROMES
  - CORNELIA DE LANGE
  - CRI DU CHAT
  - PRADER WILLI SYNDROME
  - LESCH NYHAN SYNDROME
  - SMITH MAGENIS SYNDROME
  - LOWE SYNDROME
  - FRAGILE X
  - OTHERS

(Hardiman & McGill, 2018)
(Arron et al., 2011)

PREVALENCE OF SIB IN IDD

- 30% IN NON-RESIDENTIAL CARE SETTING
- 41% IN RESIDENTIAL CARE SETTING
- IF ASD IS PRESENT PREVALENCE RISES MARKEDLY 42-70%

(Huisman et al., 2018)

PREDICTORS OF SIB IN IDD

- PAINFUL CONDITIONS – DIGESTIVE, SKIN OTHERS
- PROFOUND COGNITIVE IMPAIRMENT
- GREATER IMPAIRMENT IN FUNCTIONING, COMMUNICATION
- YOUNGER AGE
- IMPULSIVE BEHAVIOR
- HYPERACTIVE BEHAVIOR
- ASD
- GENETIC CONDITIONS

(Oliver & Richards, 2015)

EFFECTS OF SIB

- GREATER IMPAIRMENT IN SOCIAL AND OCCUPATIONAL FUNCTIONING
- MORE RESTRICTIVE SETTING
- DISTRESS TO INDIVIDUALS, FAMILIES AND CARE GIVERS
- INCREASED CAREGIVER BURDEN
- INCREASED UTILIZATION OF RESOURCES

(Minshawi et al., 2015)

ASSESSMENT OF SELF INJURIOUS BEHAVIOR

- MULTIDISCIPLINARY APPROACH
- COMPREHENSIVE PHYSICAL EXAM
- IDENTIFY GENETIC CONDITIONS
- IDENTIFY MEDICAL CONDITIONS
- IDENTIFY PSYCHIATRIC DISORDER
- DETERMINE DEGREE OF SOCIAL IMPAIRMENT
- IDENTIFY FUNCTION OF BEHAVIOR

(Minshawi et al., 2015)

IDENTIFY FUNCTION OF SIB

- SOCIAL ATTENTION
- GAIN ACCESS TO TANGIBLE ITEMS- FOOD, TOYS,
- AVOID OR ESCAPE DEMANDS
- AUTOMATIC OR SENSORY STIMULATION
- AFFECT REGULATION

(Minshawi et al., 2015)

CASE PRESENTATION

BEHAVIORAL THEORY OF SIB

IDENTIFY

ANTECEDENT- FUNCTION OF BEHAVIOR- CONSEQUENCES

GOAL IS TO CREATE AN INDIVIDUALIZED COMPREHENSIVE BEHAVIORAL TREATMENT PLAN THAT ADDRESSES THE ANTECEDENTS, FUNCTION BEHAVIOR COMMUNICATES AND CONSEQUENCES SURROUNDING SIB

(Minshawi et al., 2015)

CATEGORIES OF ASSESSMENTS

- INDIRECT ASSESMENTS
- DIRECT ASSESMENTS
- EXPERIMENTAL FUNCTIONAL ANALYSIS

(Minshawi et al., 2015)

TREATMENT STRATEGIES

- ANTECEDENT BASED TREATMENT STRATEGIES
- REINFORCEMNT BASED STRATEGIES, POS/NEG
- EXTINCTION BASED STRATEGIES
- AUTOMATIC BASED STRATEGIES - DIFFICULT TO TREAT

(Minshawi et al., 2015)

INTERVENTIONS

- SENSORY EXTINCTION
- DIFFERENTIAL REINFORCER
- PUNISHMENT BASED INTERVENTIONS

(Minshawi et al., 2015)

BIOLOGIC THEORY OF SIB

NEUROTRANSMITTERS INVOLVED

- DOPAMINE -LNS- DEFICIENCY OF DOPAMINE, DAT
- OPIOID
- SEROTONIN (5HT)
- GABA
- GLUTAMATE

(Minshawi et al., 2015)

DOPAMINE PATHWAYS MODEL OF SIB

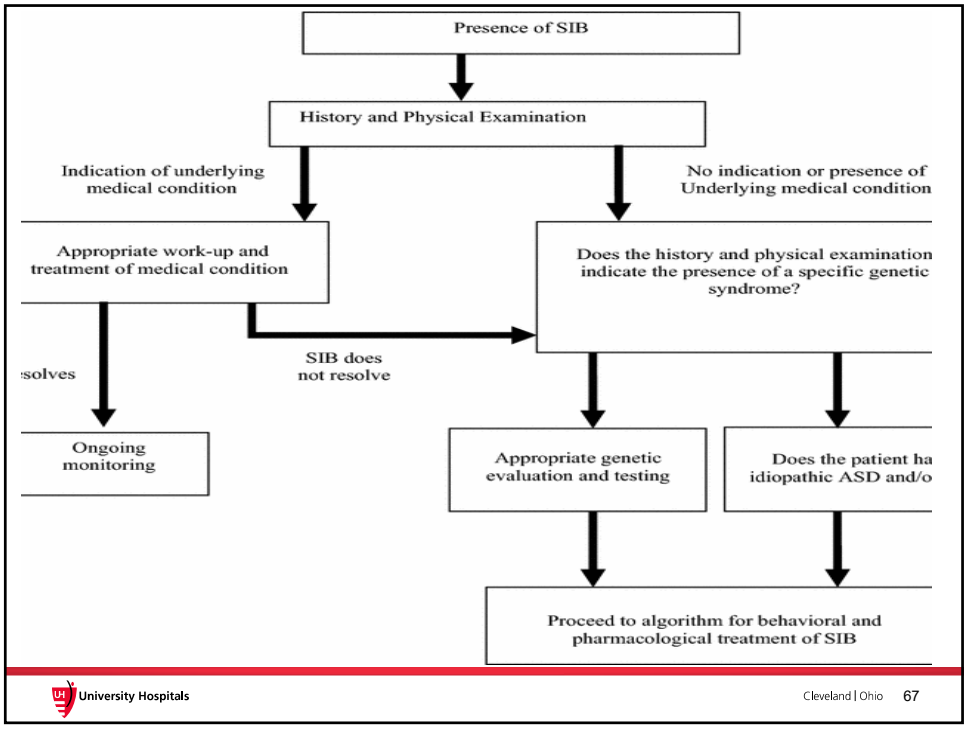
- MUCH OF WHAT IS KNOWN ABOUT DA AND SIB IS BASED ON FINDINGS IN INDIVIDUALS WITH LNS AND ANIMAL MODELS.
- SIB MAY BE A MANIFESTATION OF ALTERATIONS IN BASAL GANGLIA, CAUDATE NUCLEI, STRAITAL DOPAMINE PATHWAYS AND ASSOC NT SYSTEMS.
- STUDIES OF ANIMAL MODELS HAVE SHOWN THAT PEMOLINE CHANGES METABOLIC ACTIVITY IN THE LIMBIC, HYPOTHALAMIC AND STRIATAL STRUCTURE.

(Minshawi et al., 2015)

ENDORPHIN MODEL OF SIB

- ENDORPHINS RELEASED IN RESPONSE TO PAIN CAUSE ADDICTION
- ELEVATED ENDORHINS DUE TO PAIN AND ANXIETY – HYPOSENSITIVITY
- DYSREGULATED POMC/OPIOD SYSTEM
- DOPAMINE RECEPTOR SENSITIVITY

(Minshawi et al., 2015)


Presence of SIB
History and Physical Examination
Indication of underlying medical condition
No indication or presence of Underlying medical condition
Appropriate work-up and treatment of medical condition
Does the history and physical examination indicate the presence of a specific genetic syndrome?
solves
SIB does not resolve
Ongoing monitoring
Appropriate genetic evaluation and testing
Does the patient ha idiopathic ASD and/o
Proceed to algorithm for behavioral and pharmacological treatment of SIB
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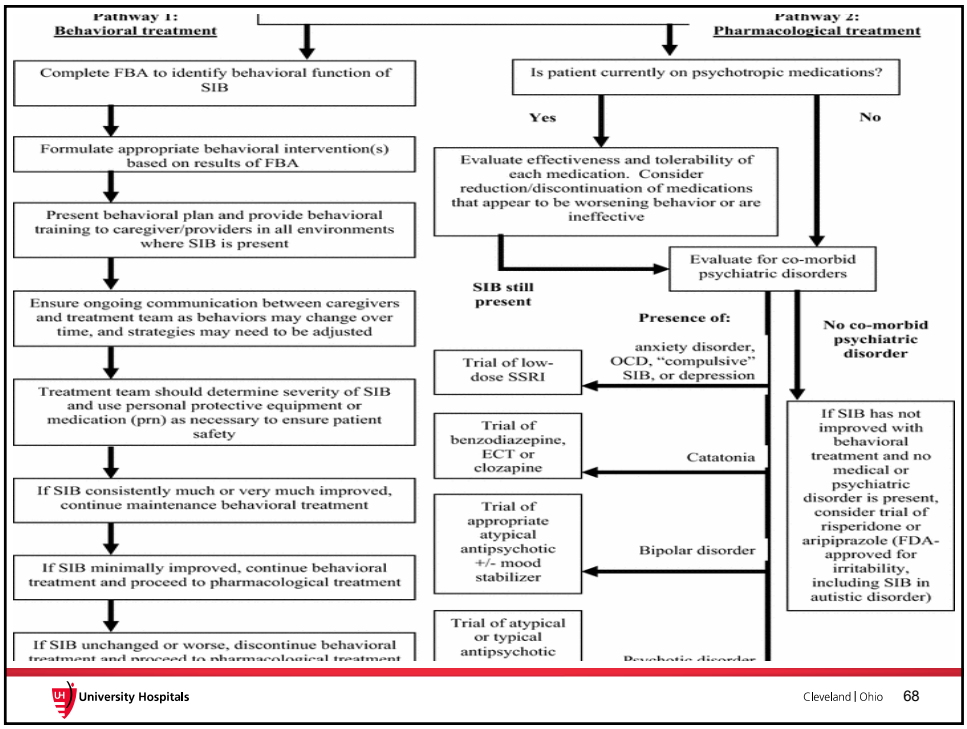
Pathway 1: Behavioral treatment
Pathway 2: Pharmacological treatment
Complete FBA to identify behavioral function of SIB
Formulate appropriate behavioral intervention(s) based on results of FBA
Present behavioral plan and provide behavioral training to caregiver/providers in all environments where SIB is present
Ensure ongoing communication between caregivers and treatment team as behaviors may change over time, and strategies may need to be adjusted
Treatment team should determine severity of SIB and use personal protective equipment or medication (prn) as necessary to ensure patient safety
If SIB consistently much or very much improved, continue maintenance behavioral treatment
If SIB minimally improved, continue behavioral treatment and proceed to pharmacological treatment
If SIB unchanged or worse, discontinue behavioral
Is patient currently on psychotropic medications?
Yes
No
Evaluate effectiveness and tolerability of each medication. Consider reduction/discontinuation of medications that appear to be worsening behavior or are ineffective
Evaluate for co-morbid psychiatric disorders
SIB still present
Presence of:
No co-morbid psychiatric disorder
anxiety disorder, OCD, "compulsive" SIB, or depression
Trial of low-dose SSRI
Trial of benzodiazepine, ECT or clozapine
Catatonia
Trial of appropriate atypical antipsychotic +/- mood stabilizer
Bipolar disorder
Trial of atypical or typical antipsychotic
If SIB has not improved with behavioral treatment and no medical or psychiatric disorder is present, consider trial of risperidone or aripiprazole (FDA-approved for irritability, including SIB in autistic disorder)
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PHARMACOLOGICAL TREATMENT

NALTREXONE
ATYPICAL ANTIPSYCHOTICS
CLOMIPRAMINE
SSRI
NAC
5HTP
BUSPIRONE
LITHIUM
AEDS
ECT
SAMe

- COCHRANE REVIEW PHARM. INTERVENTIONS FOR SIB IN ID
- WEAK EVIDENCE MEDICATION IS SUPERIOR TO PLACEBO
- NO DEFINITE CONCLUSION

(Gormez et al., 2014)

TREATMENT PLAN

- MULTI DISCIPLINARY APPRAOCH
- EVALUATE FOR MEDICAL CONDITIONS
- EVALUATE FOR PSYCHIATRIC DIAGNOSIS
- FUNCTIONAL BEHAVIORAL ANALYSIS
- +/- BEHAVIORAL TREATMENT PLAN
- CONSIDER PHARMACOLOGIAL TREATMENT IF BEHAVIORAL TREATMENT INEFFECTIVE OR TO AUGMENT IF NECESSARY.

Sexualized Challenging Behaviors

Tom Scheidemantel, MD

Sexualized Challenging Behaviors (SCB)

- Many extremely important and relevant issues relating to sex and sexuality in individuals with ID
- We will NOT be discussing the following issues today:

1. Ethical aspects of sex and reproduction in persons with IDD
2. Legal or forensic issues relating to persons with ID charged with sexual offenses
3. Prevalence or treatment of sexual abuse or victimization in persons with ID

Sexualized Challenging Behaviors (SCB) & Paraphilias

- Some overlap between SCBs and paraphilia
- The behaviors most commonly conceptualized as SCBs often do not have an associated element of sexual arousal, or fantasies/urges which are core elements of the paraphilic disorders

Defining SCB

- Deemed inappropriate by virtue of the **nature** & **setting**
- **Self-directed**
  - Masturbation or self-touching
- **Other-directed: Consensual or Non-consensual**
  - Targeting or fixation
  - Touch or contact
  - Invasion of personal space
  - Exposure
  - Language, speech, or other communication

(Lockhart et al., 2009)

Epidemiology of SCB

- Prevalence data generally lacking overall or unreliable at best
- Difficulty in having family or staff consistently or accurately observe and record behaviors which can cause discomfort for both participant and observer
- Previous data has tended to focus on sexual offenders and sexual victimization in the ID population

SCB Predisposing Factors

- Many individuals with ID lack opportunities to explore sexuality in a normative way
- Often not provided adequate education about socio-sexual norms, or not taught in a manner adapted to level of cognitive ability
- Past history of sexual abuse
- Lack of privacy in residential settings
- Impaired ability to recognize and express emotions

Non-Pharmacological Interventions for SCB

- Behavioral or psychological interventions should always be first-line or used along with any pharmacological intervention
- Behavioral interventions have proven to be helpful
  - Functional behavioral analysis (FBA)
  - DRO and DRI
- Focused socio-sexual education about relationships and boundaries
- Expanded opportunities for appropriate, healthy, normative sexual expression

(Clay et al., 2018)

Pharmacological Interventions for SCB

- SSRIs or other anti-depressants
  - Postulated to help reduce O/C thoughts or behaviors, anxiety, & impulsivity
  - Non-specific reduction in libido
  - Open-label trials of **fluvoxamine, fluoxetine, & sertraline** in treating SCB with some modest benefit
  - Systematic review by McLay et al. identified 3 small studies in the Child-Adolescent population utilizing **mirtazapine** suggesting benefit

(Sajith et al., 2008)

Pharmacological Interventions for SCB

- Anti-androgen therapy
  - Medroxyprogesterone
  - GnRH agonists (triptorelin, leuprorelin, goserelin)
- Most studies involving individuals with ID are small open-label trials or case reports
- Potential side effects
  - Weight gain, loss of bone mineral density, anemia, gynecomastia, galactorrhea
  - Not a strong connection between CV or thromboembolic events with use of anti-androgen therapies

(Sajith et al., 2008)

Medroxyprogesterone acetate (MPA, Provera®)

- Pre-treatment
  - Total testosterone
  - LH, FSH, PRL
  - LFTs, CBC, glucose
  - Weight & BP
- Contraindications
  - H/O thromboembolic disorders, liver failure, pituitary pathology
  - NOT to be used in pts < 18 years of age

(Adapted from Reilly et al., 2000)

Medroxyprogesterone acetate (MPA, Provera®)

- Dosing
  - Oral 100mg-500mg daily
  - Depo 100mg-600mg IM weekly
- Monitoring
  - Total testosterone monthly x4 mos then Q6 mos
  - Adequate T suppression at < 100 ng/dL
  - FSH, LH, PRL Q6 mos
  - Weight & BP at each office visit
  - Bone scan when T adequately suppressed then annually

(Adapted from Reilly et al., 2000)

Pharmacological Interventions for SCB

- Other reported treatments (but overall very little supporting evidence)
- Beta blockers
  - Propranolol
- Antipsychotics
  - Both 1st and 2nd generation agents
- Mood stabilizers
  - Valproate & lithium

(Sajith et al., 2008)

Pharmacological Interventions for SCB

- Naltrexone
  - Opiate receptor antagonist
  - Few small studies or case series compulsive sexual behaviors alone or in combination with other medications
  - Adult dosing starts at 50mg per day and titrate upward in 50mg per day increments
  - LFTs should be checked prior to initiating treatment
  - Common side effects include abdominal pain, anorexia, nausea

(Raymond et al., 2010)

SUMMARY & FINAL THOUGHTS

From the World Psychiatric Association international guide to prescribing psychotropic medication for the management of problem behaviours in adults with intellectual disabilities

World Psychiatric Association Guidelines

"To provide **advice to people** who are **considering** the prescription of **medication to manage problem behaviour** among adults with ID."

"Guide **neither recommends nor refutes** the use of medication."

"Decision must be taken **after careful consideration** of all the possible **benefits and potential risks**."

World Psychiatric Association Guidelines

GENERAL PRINCIPLES

Assessment and formulation

- **Identify** the underlying **cause**
- Assessment of **causes and consequences** of behavior
- **Input from family/caregivers** and multi-disciplines

Formulation should be made even in absence of diagnosis

- **Input from person** with ID and families/caregivers
- **Multidisciplinary input**
- **Monitoring** the **effectiveness** of intervention
- **Monitoring** possible **adverse effects**

World Psychiatric Association Guidelines

GENERAL PRINCIPLES

- Revisit and **re-evaluate** the **formulation** at regular intervals
- Prescribing should be part of **broad person-centered** care plan
- Plan should be **communicated clearly** to the person/family
- Need an **assessment of capacity** to give **informed consent**

World Psychiatric Association Guidelines

MAIN RECOMMENDATIONS

- Use medications only within **best interest** of the person
- All **non-medication options** should have been considered
- Take into account **cost-effectiveness**
- What worked before, and what did not?
- If **previous** interventions caused **AE, should be noted**
- Availability and non-availability of services/therapies
- Local/national **protocols and guidelines** should be followed

World Psychiatric Association Guidelines

ONCE DECISION TO PRESCRIBE IS MADE:

- Ensure appropriate **PE and investigation**
- **Blood tests and EKGs** at regular intervals
- **Clarify** to person/family if drug use is **off-label**
- **ID a key person** to ensure appropriate administration
- Provide person/family with **copy of treatment plan**
- Have **objective way** to **assess outcomes** including **AE**

World Psychiatric Association Guidelines

ONCE DECISION TO PRESCRIBE IS MADE:

- Arrange **appropriate follow-up** assessments
- **One medication at a time**
- Use within **recommended doses**
- **Doses above** recommended **only exceptional** cases
- **Start low** and **titrate slowly**
- **Lowest required dose**, for the **minimum time** necessary
- **Consideration for withdrawing** medication ongoing

World Psychiatric Association Guidelines

ADVERSE EVENTS

- **No quality evidence to support or refute that persons with ID are a at greater risk for AE**
- Discuss with person/family any common and serious AE
- Advise what action to take for a serious AE
- All AE should be recorded properly

World Psychiatric Association Guidelines

CHOICE OF MEDICATION

- Not possible to recommend specific medication
- Once prescribed, evaluate risk-benefit profile regularly
- Consideration of reduction/withdrawal should be ongoing
- Should be a relapse management plan
- Be aware of the withdrawal effect of certain medications
- Always consider non-medication based interventions
- Lack of studies of combinations of medications
- Not possible to recommend any combination
- Observational studies suggest reduction in polypharmacy improves behaviour and quality of life

World Psychiatric Association Guidelines

ADD-ON MEDICATIONS

- If ineffective, reassess
- If continuing the first medication, reasons for two must be recorded
- Use of two from same class is not recommended
- If combination effective, try to withdraw or reduce the first medication
- Always consider a non-medication intervention
- Try to return to monotherapy as soon as possible
- Avoid using two medications for the same indication
- Use more than two medications only in exceptional circumstances
- Try to secure another clinician's opinion in that case.
- Use of > three medications is difficult to justify, except in epilepsy

World Psychiatric Association Guidelines

WITHDRAWING MEDICATION

- Studies show that in a proportion of cases, medications can be withdrawn
- Withdraw one medication at a time
- Withdraw medications slowly
- If necessary, allow time after withdrawing one to withdraw another

World Psychiatric Association Guidelines

Additional Specific Psychotropic Recommendations:

- Avoid frequent drug and dose changes
- Minimize long-term use of PRN psychotropics
- Avoid long-term use of benzodiazepines
- Avoid long-term use of sedative hypnotics
- Minimize long-term use of anticholinergics, w/ or w/o EPS
- Minimize use of high-dose antipsychotics
- Avoid use of DPH or barbiturates as psychotropics
- Avoid the use of intra-class polypharmacy

World Psychiatric Association Guidelines

Altogether, there are about 50 of these guidelines for psychotropic practice in persons with dual diagnoses.

A “Best Practice” guideline should be to regularly audit one’s patients or program, to determine how close/far one is from regularly meeting these 50 guidelines

(xx/50= ?% compliance)

CONCLUSIONS

- Persons with ID can and do suffer from the entire range of psychiatric illness
- Psychiatric illness in persons with ID is common, but often difficult to diagnose
- As a result, treatment approaches in persons with ID is often symptom-based, rather than syndrome or etiology-based

CONCLUSIONS

Behavioral problems often co-exist with psychiatric illness

Psychotropic medications should be only one part of combined treatment, also utilizing behavioral and psychosocial treatments

When utilized, psychotropic medications should preferentially be used to treat specific psychiatric disorders, rather than to treat symptoms

CONCLUSIONS

When psychotropic medications are utilized, for psychiatric disorders, and/or behavioral problems:

Follow the WPA Guidelines, incorporating

- Systematic assessment
- Multidisciplinary participation
- Informed consent
- Regular monitoring for response & AEs

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