Obsessive-Compulsive Disorder in Autism & Related Disabilities

Travis Thompson, PhD, LP
Special Education Program
Dept of Educational Psychology
University of Minnesota
Minneapolis, MN, USA

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Crisis Intervention vs. Preventing Crises

- Violent situations that are out of control and risk harm to client and others require crisis response teams
- Putting out a fire may be essential, but not the same as preventing the next one
- The focus of my presentation is on reducing and preventing behavioral and emotional outbursts
RITUAL OR REPETITIVE ACTIVITIES
Intolerance for Changes in Routines
Motor Stereotypies
Restricted and/or Perseverative Interests
Though people with autism share common traits, Remember.....
They differ widely...

Alan Turing, WW2 Computer Genius

Young Man with Typical Hand Flapping
OCD is quite common in the General Population & Very Common in Autism

3.3 million people in the US have OCD, About 1 in 5 or 6 people with autism also meet the DSM criteria for OCD and many more have milder symptoms of OCD.

Michelangelo is believed to have had OCD. Not at all a social person and highly perfectionistic. Avoided people most of the time and sometimes would even walk out of a conversation for no apparent reason.
Compulsive & Repetitive Behavior Takes Various forms in Autism

All Repetitive Behavior in Autism IS NOT a type of Obsessive Compulsive Disorder... but some is.

Lets first consider different types of repetitive, rigid and compulsive behavior in Autism
Four Year Old Self-Stimulating while peers play interactively
Sometimes the Behavior Takes the Form of Rigidity When Things Don’t Go as Expected
Repetitive Stereotypic Behavior and Thoughts in Autism and IDDs

Subtypes of Repetitive Behavior

- Repetitive Motor Behavior; such as rocking, flapping, twirling, finger flicking, holding pieces of string or paper; associated with lower IQ, lack of language. *Not Usually familial*
- Insistence on Sameness. *Is Familial*
- Circumscribed interests. *Is Familial*

Untreated stereotypies can morph into self-injury

Repetitive Motor Behavior

- Usually are not maintained by attention from caregivers.
- May be maintained by escape from disliked, difficult or disturbing activities.
- Often appear as “automatic reinforcement” in FAST and ABC analysis... that basically means you don’t fully understand why the person is doing it.
Insistence on Sameness & Circumscribed Interests

Often a Form of Obsessive Compulsive Behavior

1. Behavioral Treatments
2. Behavior Management Methods
3. Medication Management Methods
Obsessions & Compulsions

**Obsessions**

**Compulsions**
- repetitive behaviors or mental acts that a person feels driven to perform in response to an obsession, or according to “rules” that must be applied rigidly. [J.E.D. Esquirol 1938 & D.H. Tuke, 1894]
OCD in Autism...Not The Same

**Obsessions**
- Preferred topics, circumscribed interests, found mainly in higher functioning individuals (e.g. Dogs)
- May be unable to stop thinking about a specific idea or thought

**Compulsions**
- Specific repetitive activities, e.g. flipping light switches, opening & closing doors, insisting that toys are lined up by size in a specific order
- Insistence on sameness
Typical Compulsive Routine seen in 2 Yr Old With Autism
Do Affected People Realize Symptoms Are Not “Normal”?

<table>
<thead>
<tr>
<th>Neurotypical Individuals</th>
<th>Autism and IDDs</th>
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<td>Symptoms go against the person’s concept of themselves, causing great distress. They may go to great ends to suppress their compulsive behavior or conceal their obsessions.</td>
<td>Unaware of the degree of intrusiveness of the OCD symptoms. May seem to feel they are not unusual and accept them. May not understand why other people are bothered by them.</td>
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Autism and OCD Overlap, But Not Identical

Ruta (2009) Studied Youths 8-15 years, matched for age, gender & IQ

Three groups: ASD, OCD and Controls

ASD group more _Hoarding_ obsessions & _Repeating, Ordering_ and Hoarding compulsions compared to Controls.

OCD group, more Contamination and Aggressive obsessions and Checking compulsions compared to ASD group and controls.

Neither ASD or OCD group aware of exaggerated nature of their symptoms

Autistic Traits in OCD

Pediatric patients with diagnosed obsessive-compulsive disorder (n=109)

Parent ratings of the Autistic Symptom/Syndrome Questionnaire

Found that ASD traits are prevalent in children with OCD but not diagnosed with autism

Ivarsson & Melin (2008) *Autism spectrum traits in children and adolescents with obsessive-compulsive disorder (OCD)*

*Anxiety Disord.* 22(6):969-78.
High Functioning ASD vs. OCD

Children with ASD and children with OCD were compared on a range of repetitive behaviors.

Children with OCD reported more compulsions and obsessions than children with ASD & both were more than controls.

Types of compulsions and obsessions tended to be less sophisticated in children with ASD than those with OCD.

Not Simply “Bad Habits”

- Repetitive rituals, such as rocking, flapping hands, checking, lining up or talking incessantly about one topic (e.g. weather), are not “psychological bad habits.”

There is strong evidence for a brain basis for OCD symptoms, including those associated with autism.
Brain Basis of OCD Symptoms

Studied Basal Ganglia at base of the brain of Individuals with OCD using Brain Imaging

Right caudate and total putamen volumes correlated positively with higher order OCD-like repetitive behaviors

**Hypothesis:** Orbiofrontal Cortex is hyperactive in OCD, reflecting ruminative preoccupation with future aversive events.

fMRI measures of brain activity of OCD and matched controls.

Their frontal cortex indicated they were worriers about future bad things happening.

Summary: Neural Basis of OCD in Autism

OCD in Autism is linked to abnormalities in specific brain areas that are the same as those involved in children diagnosed with OCD but NOT autism.

On fMRI testing, most of these same structures show differences in people with autism.

Is OCD an Anxiety Disorder Or a Separate Condition?

“As OCD and other putative OC Related Disorders share aspects of brain abnormalities, familial and genetic factors, and treatment response, it has been proposed to add a new diagnostic category in DSM-V entitled OCRDs.”

Anxiety Exaggerates Rituals
Young Girl Diagnosed PDD-NOS
Anxiety-OCD Interactions

Although OCD May Not Be an Anxiety Disorder, OCD Symptoms Are Exaggerated by Anxiety
Exposure and response prevention involves repeated exposure to the source of your obsession. The person is asked to refrain from the compulsive behavior s/he would usually perform to reduce their anxiety.

This method has been used with some success with Higher functioning individuals with Asperger disorder, or PDD-NOS (atypical autism).
Behavioral Treatment 2

*Desensitization and Response Prevention*

Similar to “Exposure + Prevention” Except the stimulus associated with OCD behavior is initially very weak and unlikely to provoke serious OCD symptoms.

Over repeated exposures, provocative stimulus is made stronger, while teaching person to engage in an incompatible response.

Reinforce for successfully engaging in an alternative to the OCD behavior.
Desensitization

Six Step Desensitization to Frightening Dogs

1. Stuffed Toy Dog Across the Room
2. Stuffed Toy Dog Next to Child
3. Small Dog Across the Room
4. Small Dog Next to Child
5. Large Dog Across the Room
6. Large Dog Next to Child
Behavioral Treatment 3

Cognitive Behavior Therapy

Tony Atwood’s “Emotional Toolbox”

1. Physical Tools: e.g. going for a run
2. Relaxation Tools: e.g. listening to calming music in solitude
3. Social Tools: e.g. spending time with supportive relative or a pet
4. Thinking Tools: e.g. self-talk, “I can stay calm”
5. Special Interest Tools: e.g. activities that “turn off” the urge to do the OCD activity

[Limited empirical evidence, mainly from kids with Asperger disorder. Seems to be effective with some higher functioning kids.]
Habit Reversal Training

1. **awareness training**… teacher holds up finger when child is engaging in behavior in school
2. **competing response training**… use hands for another activity instead of finger-flicking
3. **contingency management**… child earns stars exchangable for back up reinforcer for meeting goal
4. **relaxation training**… teach child to use breathing exercises when urge to engage in OCD behavior
5. **generalization training**… once successful in classroom or at home, practice in other settings

Douglas Woods, Marquette University, originally used for treating Tourette’s syndrome tics & trichilomania
Behavioral Treatments 5

Managing Compulsive Rituals: Doing Battle with the OCD “Beast”
[next four slides]

1. Limiting time when OCD behavior may be done, & using access to OCD activities as a reinforcer for non-OCD behavior (capitalizes on adherence to routines)

2. Limiting situations in which OCD behavior may be exhibited

3. Eliminating stimuli that provoke OCD behavior
Limiting time when OCD behavior may be done

1. Use timer or visual schedule to indicate specific intervals within which OCD behavior can be done.

2. Schedule times so they occur shortly before another highly desirable activity (e.g. a meal, or going outdoors to play) so there is an incentive to stop OCD behavior.

3. Lengthen interval between OCD opportunities and shorten duration of opportunities.
Limiting Available OCD Time

[Example]

1. Provide 5 minutes before lunch for OCD, before dinner and before bedtime.

2. Each OCD behavior that occurs at other times shortens the next OCD opportunity by 30 seconds; Don’t cajole the child; Let the behavior and consequence speak for itself. Say, “Oops, you twirled in circles, now you have 4 minutes private time before dinner.”

3. After each week when the child succeeds in limiting most of his/her OCD behavior to specified allotted time, shorten the next week’s OCD opportunity duration by one minute.

4. After two weeks schedule opportunities twice a day, and after 3 weeks once a day, and after one month, eliminate OCD opportunity.
Limiting Situations OCD Behavior May Occur

1. Purpose: to make certain OCD behavior is not being inadvertently reinforced by attention.

2. Week 1. Tell client s/he can only engage in the target behavior in their own room. This is to encourage cooperation, but limit social opportunities associated with OCD behavior.

3. After leaving their room, engage the client in a constructive activity. Do not discuss the target behavior with them.

4. After a week tell client s/he can only engage in target behavior in a guest room after removing TV’s, video games, mirrors, toys that make noise, and other visually stimulating items.

5. Often after several weeks the client/child will lose interest and stop engaging in the OCD behavior
Eliminate Stimuli Provoking OCD Behavior

1. Television
2. Computers
3. Boom Boxes
4. Toys with built in music players
5. Mini-trampoline
6. Rocking horses
7. Hanging furnishings that shine, glitter or twirl (e.g. mobiles, curtain walls)
8. Mirrors or other reflective surfaces
9. If there are any walls, floors or ceilings that have embedded glitter, consider repainting with a flat paint or covering.

I generally recommend items 1-7 are only in one room of the house that is usually not available to the youngster with autism except under supervision. As much as possible, eliminate 8 and 10, and limit mirrors to the bathroom. Cover other shiny surfaces.
Break
Compulsive Behavior and Self-injury

- Some forms of self-stimulatory, compulsive ritualistic behavior leads to caregiver attention, and is inadvertently reinforced.

- Over time, caregivers differentially attend to increasingly intense or severe bouts of self hitting or self biting.

- It may be difficult to effectively treat such behavior using behavioral methods alone.
Hand-Slapping Transforming into Self-Injury
Self-Injury Can Become Chronic & Intractable if Not Treated Early in Life
A YOUNG WOMAN WITH AUTISM AND EXTREME AGGRESSION AND SELF-INJURY
Identify circumstances leading to self injury, & maintaining consequences

• M.W: 14 yr old boy with autism and severe/profound IDD engaged in head banging and self biting in a special education classroom
Approx. 2/3 of his self injury led to teacher or instructional assistant attention, or escape from an activity he didn’t like or was unable to do well.
Interventions for Self Injury Based on Functional Assessment

- Interventions: Augmentative Communication Instruction
  - Leave Taking Request (Iconic request)
  - Request for Attention (Gestural request)
Focus on Brain’s Natural Opiates

• **Naltrexone blocks brain opiate receptors so beta endorphin, though released, cannot bind to the opioid receptors.**

• Mu brain receptor mediates both analgesia as well as “high” when opiate addicts inject heroin.

• When the individual self-injures after naltrexone, beta endorphin is released, but can’t bind to the opiate receptors.
What Do We Know About Effects of Naltrexone on Self Injury?


- 8 Adults (29-41 yrs) with Severe IDD residing in a large public residential program; Most would also meet Dx for autism

- 3 forms of SIB identified for each person... had been unresponsive to previous treatments

- Randomly assigned to naltrexone or placebo for successive 3 week blocks (N, P, N, P)
Naltrexone Reduced Head Blows and Hand/Wrist Biting
M.W., who we discussed earlier, displayed SIB 50 times per day in the classroom during baseline assessment.

We implemented an augmentative communication system for him… but roughly 1/3 of M.W.’s self-injury did not appear to be socially motivated, i.e., it seemed to be maintained by the neurochemical consequences of self-injuring.

When naltrexone + augmentative communication were combined, SIB dropped to near zero. [Symons, Fox & Thompson, 1997; Appl. Rsch. Intell. Disabilities, 10, ]
Adverse Effects of Naltrexone?

- No significant side effects with over 400 cases; we have seen two of 40 people we have treated display modest reversible low blood pressure and pulse decrease.

- Physician’s Desk Reference in US includes warning of possible liver toxicity in high naltrexone dosages; we have used dosages 1/3 those at which toxicity reported.
Body Areas where people with autism & severe IDD self injure

- 80% of SIB directed at 5% of body surface
- Primary sites on forehead and sides of head, and hands

[Symons & Thompson, 1997, J. Int. Disabilities Research, 41]
Why do People Who Self Injure, Focus on Specific Body Areas?

Correlation of +.66 (p< .038) between plasma Beta Endorphin increases following SIB and Change in SIB from Baseline by Naltrexone Treatment (2 mg/kg) [2 mg/kg = ~ 150 mg for a 150 lb person]

Sandman, Hetrick, Taylor & Chicz-DeMet (1997) AJMR, 102, pps. 182-199
Synthesis of SIB Studies

- Synthesis of peer-reviewed publications (1983 to 2003) documenting use of naltrexone (SIB) were analyzed.

- 27 research articles (86 S’s) w/SIB. 80% improved relative to baseline during naltrexone & 47% of subjects SIB reduced by 50% or greater.

- Better outcomes than other medications.

Severe SIB Case Example: KR

- KR: 23 year old man with Autism
- Client background
- Residential placement history
- Behavioral & medication intervention histories
- Primary behavioral challenges
- Intervention strategies
  - Communication
  - Domestic & Self-care
  - Leisure recreation
Case Example: Ken

- Interview parents and staff regarding interests and problem areas
- Evaluate likes and dislikes in natural environments; Don’t take anything for granted
- Identify setting events
- Track triggers
- Identify self-injurious behaviors that serve same functions
- Identify consequences maintaining self injury
Client Background

- **History:** Normal pregnancy and delivery. Noticed “odd behavior” at 2 years . . . Lack of speech, staring, afraid of sounds
- **Mental Age:** 3 years (*probably inaccurate*)
- **IDD Level:** Moderate/Severe (*high moderate*)
- **Previous Diagnoses:**
  - Early Childhood Autism with moderate to severe retardation
  - Possible partial complex seizures (history)
  - Possible major affective disorder
Extensive Compulsive Self-Injury

- 1974-5: Digging and poking at his chest; severe lesions.
- 1977: Poked fingers up nose, caused severe bleeding; pulled genitals and threw self into air against walls and floor.
- 1978: 194 severe tantrums, most of the time in restraints over 6 months.
- 1980: Removed 2 teeth with his fingers; bit through cheek.
- 1982: Bit off part of tongue; tore off several inches of his lip.
Primary Behavioral Challenges
(cont.)

- 1983: Removed 5 more teeth with his fingers; bit through his cheek.
- 1984-5: Bit hand, mashed his nose into his face until it bleeds, tearing at lip.
- 1986: Smashed his head into windows and mirrors causing facial lacerations and severe bleeding.
- 1986: Bit off piece of heel of his hand

- At Christmas 1986 Began Community Intervention Program
Residential Placement History

- Natural home until age 9
- Two community residential facilities (for 6 yrs.)
- 19 Specialized residential facilities for people with IDDs and behavior problems refused to serve him
- Demitted to parents home...emergency admission to acute hospital
- Two state residential facilities (for 3 years)
- Two community foster homes (for 4 years)
- Multiple emergency admissions to psychiatric units at local hospitals, and emergency room visits for SIB injuries
Intervention History

Primary Behavioral Interventions

- DRO 30 minutes
- Relaxation Training
- Time Out Ribbon
- Basket hold restraint
- Posie restraint (foster home)
- Informal positive reinforcement for adaptive behavior (foster home)
- Community Outings (foster home)
- Time out in his room (foster home)
- Variations on the above
Intervention History
Medication Treatment

- Chloral Hydrate
- Dilantin (Phenytoin)
- Sinequan (Doxepin)
- Haldol (Haloperidol)
- Tofranil (Imipramine)
- Lithium

- Mellaril (Thioridazine)
- Serax (Oxazepam)
- Tegretol (Carbemazepine)
- Navane (Tiothixene)
- Valium (Diazepam)
Ken’s Intervention Team

- Mary Piggott, MS, Team Coordinator
- Travis Thompson, PhD, Supervising Psychologist
- Joe Reichle, PhD, Communication Consultant
- Stuart Schleien, PhD, Therapeutic Recreation Consultant
- George Realmuto, MD, Psychiatric Consultant
- Steve Kodluboy, MSW, Ken’s case manager
- Residential Representative
- Vocational Program Representative
- County Financial Manager
Steps in KR’s Functional Behavioral Assessment

- Assess KR’s strengths and interests
- Assess environmental opportunities
- Identify KR’s critical skill deficits
- Record distribution of behavior challenges over the day (Touchette Scatter Plot)
- Track setting events
- Monitor triggers
- Identify various behavior challenges that may serve the same function
- Track consequences
Results of KR’s 2-Week Assessment #1

- No functional communication

- Interested in outdoor activities, swimming, pinball, vacuming, and meal preparation; good manual dexterity

- Socially interested, but minimal social skills

- Few opportunities for normal behavior because of fear of SIB outburst, especially in community settings; No friends
Results of KR’s 2-Week Assessment #1

- Physical illness or loss of an anticipated activity appeared to be setting events (e.g. such as forthcoming visit by his mother)

- Noisy, crowded places with unfamiliar people or frightening stimuli (e.g. large zoo animals, thunder, strong unusual smells) reliable triggers

- Hyperventilation and rocking front to back were behavioral antecedents to SIB outburst; All forms of SIB interchangeable; No aggression

- SIB Motivation: escape./avoidance of intolerable situations
Communication Intervention

- Message board - % independence each step of task analysis twice daily icon communication (also done 2-4 times a day in day program)

- Used photos of Ken engaging in activities, photos of tangibles (e.g. Big Mac) and places he liked to go (e.g Pinball arcade).

- Reduced photos to 1” square and laminated in plastic and attached Velcro to the back
Daily “to do” Icon Board
Icon Wallet
Domestic

• Laundry-task analysis - weekly % of independence
• Making lunch-task analysis - 5 days a week data on a % basis
• Bed-making-weekly% independent completion

Self-Care

• Care of eye glasses - daily data % independence on task analysis
• Shaving - daily data % independence on task analysis
• Independent showering- daily time to completion
Ken Took Great Interest in Daily Chores

Limited Training Based on Task Analyses Was Required For Him To Learn Most Daily Living Activities
Domestic Skills: Vacuuming
Domestic Skills: Bed Making
Domestic Skills: Serving Beverages To Self & Others
Ken Enjoyed His Job and Took Satisfaction in Working Alongside Typical Workers
Leisure/Recreation Activities

• Pinball 8-9 times per week - % independence of task analysis

• Simon 5-6 times per week - % of independence of task analysis

• Bowling once per week - % independent responses

• Horseshoes & Bocce Ball 1-2X weekly
  % independent responses at park with elders; increase communication

• YMCA workout 3-4 times per week
Ken Enjoyed Working Out at the YMCA
After About a Year, Ken Had a New Life Which has Been Sustained for 15 Years
Reduction in Self-Injury

- There was no specific intervention targeted at self-injury.
- For 3 months prior to starting the Community Intervention Program Ken was in restraints 20 out of 24 hours.
- Beginning the first day of the program the restraints were removed and locked in a closet.
- All meds were gradually discontinued except doxepin.
- Ken’s self-injury decreased and then stopped over six months.
KR’s Self-Injury Has Remained Nero Zero for the Past 26 Years
THE CALMING OF KENNY

Ken Regnier pulled out his own teeth, banged his head, bit off part of his tongue. Something had to be done to protect him from himself.

Inside: The latest in cellular phones
Follow Up With Ken 2 Years Later, Living in a Typical Community Residence in West St. Paul, MN Holding a Job, No Longer Engaging in Self Injury
Role of Medications in OCD

• Understandable Concern among parents about using medications

• Bear in mind OCD symptoms are very heavily driven by brain chemical differences

• Anti-anxiety medications are often very helpful in treating OCD symptoms in conjunction with behavioral intervention
For More Information

Paul H. Brookes Publishing Company

http://www.travisithompson.net
Thanks For Your Attention...

- Travis Thompson
  - thomp199@umn.edu
  - travisthompson2@comcast.net