



Assessment and Treatment Of Obsessive Compulsive Disorder in DDMI Population

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Individuals with Intellectual Disability

Mental Illness in Adults with I/DD

1980s

- General belief people with I/DD did not have a cognitive capacity to experience mental health problems
- Behavioral disturbances were attributable to their learning disability.

Last 25 years

- Significant interest and effort to understand and expand knowledge of mental health problems in I/DD
- Care shifted from state hospitals to community setting which
- Increases need for medical and psychiatric care in community
- Created barriers to accurate assessment and intervention

Today

- Accepted that people with I/DD experience mental illness as nondisabled do
- More vulnerable
- Studies measuring prevalence rates and factors I/DD
- Produce different and sometimes contradictory results

Mental Illness I/DD vs General Population

- Prevalence psychiatric disorders higher- 32-40%
- Easier to diagnose in mild I/DD than severe
- Rates of depression at least approach – if not exceed
- Typically more severe
- More difficult to diagnose
- Degree of variability of cases greater

(Aggarwal 2013)

Mental Illness in Adults with I/DD

- Difficult to obtain **accurate** data..
- What **interferes** with obtaining accurate data?
 - Communication of internal state/symptoms difficult
 - **Absence of recognition by caregivers/providers**
 - Data obtained from different settings, study designs, definitions
 - **Definitions of different severities of depression and ID**

What is the Reality?

- 62% of people with ID and mental health needs do not receive services (Fletcher, 1988)
- 75% of psychiatrists feel they do not have sufficient training, 39% would prefer not to treat (Lennox & Chaplin, 1996)
- Internal Barriers: communication, finances, lack of self-referral
- External Barriers: fragmentation between agencies, lack of professionals with training and desire

Practitioner Issues

- Practitioners **often feel inadequate** to assess, diagnose and treat ID population, particularly if psychiatric issues in ID population.
- 90.2% of psychiatrists **felt inadequate** to diagnose problems in I/DD population due to lack of training
(Werner, 2006)
- Practitioner anxiety **can often interfere with ability to provide good care.**

Learning Objectives

- Cite prevalence (proportion of a population found to have a condition) of OCD in DDMI population
- Review the etiology of OCD
- Describe 3 DSM 5 Criteria for OCD
- Propose Treatment for OCD



Louise - 22 yr old African American female with Down Syndrome



- History of washing her hands until red, chapped and cracked

- Wiping herself repeatedly, after urinating or a bowel movement, until she is raw as she never feels “clean”





- Arranges her beanie breasts for hours sometimes at night until it is “just right” and then she’s able to go to bed, which often makes her late in the morning for work

Obsessive-Compulsive Disorder (OCD)

- Unwanted, intrusive, & repetitive thoughts (obsessions) & rituals (compulsions) from feeling of urgent need
- 1/3 to 1/2 of adult cases start when 10-12 years old
- 4th most common neurobiological illness
- 1:40 adults & 1:200 children having lifetime occurrence



Common Obsessions and Compulsions:

Obsessions

1. Concern w/order
2. Counting
3. Fear of acting on aggressive impulses (30%)
4. Fear of dirt, germs & contamination (35%)



Compulsions

1. Repetitive hand washing (75%)
2. Checking & rechecking
3. Repetitive actions such as stepping only on the cracks in the sidewalk
4. Concern with arranging.

OCD: Prevalence I/DD

Prevalence

2.5%+ for I/DD vs
1.65-2.5% nondisabled

- No clear data for DDMI
- Anxiety/OCD/stress disorders misdiagnosed as “problem behaviors”
- Difficult assess in mild I/DD
- Severe and profound learning disability only behavioral symptoms can be assessed
- Classification is also difficult as anxiety normal and appropriate reaction
- Occurs in many different psychiatric conditions
- Not specific

Down Syndrome Susceptibility to OCD

- Prevalence 1.7- 4.5%
(Myers and Pueschel 1991; Prasher, 1995)
- Ordering most common type of action/obsession
- Ritualistic touching
- Cleaning.



Down Syndrome Susceptibility to OCD



- Difficult to distinguish compulsive disorders from stereotypies in people with intellectual disabilities
- Pay attention to differential
- Obsessional repetitive thoughts can occur in people with Down's syndrome but may be difficult to diagnose.
- Obsessive-compulsive acts more likely to be detected.

Compulsions Common to General Population vs I/DD OCD

General Population

Hand-washing,

Checking

Cleaning

I/DD Population

Most common

ordering common

handwashing,

Not as often seen

cleaning

checking

Why Is Obsessive Compulsive Disorder Hard to See in Clients with I/DD?

- Atypical presentations
- Diagnostic limitations secondary to communication barriers,
- Lack of formal diagnostic tools
- Valid diagnostic information hard to obtain
- Difficulty describing internalizing symptoms
- Deficits in communication, social skills and intellectual functioning.
- Challenging behaviors may mask mental illness
- Limited number of empirical studies
- Lack of standardized assessments specific to diagnosing clients with IDs and psychiatric co morbidities

Difficulties...

Obsessional thoughts hard for people with I/DD to describe

Compulsions can be observed

Difficult to distinguish them from stereotypies, tics and autism.

Stereotypy

- Exact definition varies with different authors.
- “Fragments of a normal action that are continually repeated without purposes . . . Some may simply be reiterated bizarre purposeless acts . . . ” without conscious control, although consciousness is intact. "The movements are usually uniform, but at times incomplete forms of a given stereotypy may be observed" (Lohr and Wisniewski 1987).

Stereotypy Definitions

- Physical response
 - inner driving force such as restlessness or psychic pain
 - coordinated, patterned, repetitive, rhythmic, purposeless but seemingly purposeful or ritualistic, movement, posture or utterance" (Jankovic 1994).
- "Can be suppressed voluntarily without a buildup of inner tension," thus distinguishing them from tics (Tan et al 1997).
- "Involuntary, patterned, coordinated, repetitive, rhythmic, and nonreflexive features, (which) typically last for seconds to minutes, tend to occur in clusters, appear many times per day, and are associated with periods of stress, excitement, fatigue, or boredom" and are readily suppressible (Mahone et al 2004).
- Different than tics(Edwards et al 2012): "a non-goal-directed movement pattern that is repeated continuously for a period of time in the same form and on multiple occasions, and which is typically distractible."

Stereotypy Classification

- Simple movements

- Rocking
- Tapping
- Hugging
- Lip biting

- Complex movements

- **Ritualistic behaviors**

- Spitting into a hand & smearing it in a particular fashion
 - Running forward a set number of paces then running backwards
 - Repeated raising and lowering of the arms
 - Waving and flapping of the arms and hands
 - Finger wiggling

Assessment and Treatment Address Four Dimensions

- Biological
- Psychological
- Social
- Developmental

Assessment

- Multi disciplinary
- Thorough assessment for possible physical cause of anxiety/agitation
- Applied behavioral analysis
- Multiple resources-home, work, family, particular those who know individual for long period of time
- Any recent trauma or anniversary or LOSS?

Assessment for Mental Health Issues

Presenting
complaint

Recent life events

Changes/moves

Medical History

Medication History

Psychiatric History

Trauma History

Family History

Physical

Possible Labs

Assessment

- **Collateral info** more importation than from general population being evaluated



Full Psychiatric Assessment

- Full history (usual subheadings)
- Collateral history
- Mental state examination
- Physical examination
- Special investigations
- Reviewing previous medical case notes
- Discussion with professionals from other disciplines involved in the person's care

Special Considerations

- Capacity to consent
- Communication and engagement
- Information from carers
 - measure all psychopathology, not just that volunteered by carers
 - distinguish symptoms from long-standing traits and behaviors, gather background from information, engage carers
- Pathoplastic effect of development level on psychopathology
- Developmental history
 - level of ability
 - cause of disabilities
- Behavioural phenotypes
- Epilepsy
- Physical Health

Communicating with Person with I/DD

Context

- Allow plenty of time

Environment

- Relaxed, familiar environment (e.g. the person's own home)
- Remove physical barriers
- Comfortable seating
- Positioning to allow communication with both the person and their carer (i.e. not turning away from the person)
- Noise-free environment (turn the TV off)

Communicating with Person with I/DD

Verbal language

Active listening

Clarify to check you understand correctly

Use straightforward language and short sentences

Avoid jargon

- Avoid intellectually complex concepts (be concrete)
- Avoid complex sentence constructions such as conditional tenses
- Repeat and rephrase
- Check if the person understands
- Use open questions as far as possible
- Articulate clearly

Psychopathology Instrument for Adults with Mental Retardation (PIMRA).

- First scale for assessing psychopathology for persons with ID appeared in 1983 (Kazdin, Matson, & Senatore, 1983).
- Still widely used
- Many scales based on or cross validated
- Corresponding caregiver form

Yale-Brown Obsessive Compulsive Scale Y-BOCS

- Prader Willi
- Autism Spectrum
- Modifications in Mild Intellectual Disability

Lab Tests

- TSH
- FT4
- ECG
- Urine Drug Screen
- Chem 7
- LFT
- Pregnancy test



OCD: Course

- Course
 - Age of onset
 - Males 6 - 15 years; Females 20 - 29 years
 - Onset typically gradual, some acute
 - Chronic waxing and waning of symptoms
 - Peaks at age 11 and early adulthood
 - Stress exacerbates symptoms
 - Estimated that 15% display progressive deterioration in social & occupational functioning

The Development of OCD

- OCD symptoms typically begin during the teenage years or in early adulthood.



- However- children with I/DD can develop the disorder at earlier ages, even during the preschool years.



- Early studies suggested that at least one-third of all cases of OCD in adults without I/DD began in childhood. More recent figures suggest that as many as 80% begin in childhood (Storch, 2007)
- OCD strikes people of all ethnic groups.
- It is equally common in males and females.



The Nature of OCD Symptoms

- Compulsions often seem intended to ward off harm to the person with OCD or others they are close to.



- While performing these rituals often provides a sense of relief, this relief is usually only temporary.

The Nature of OCD

Symptoms

- Adults with this disorder often have insight into the irrational nature and senselessness of their obsessions and compulsions
- Much less common in younger children and I/DD.
- Symptoms may become less severe over time and there may be intervals where symptoms are less problematic.
- However, for most individuals the disorder tends to be chronic in nature.

OCD: Genetics

- 1st degree relatives of children & adolescents with OCD are 3 to 12 x more likely to have dx
- Earlier age on onset more frequently relatives are affected
- Twin studies greater heritability of OCD sx in children
- Later OCD occurs greater role of environmental conditions and trauma
- Disturbance of info processing in cortico-striatothalamo-cortical circuits

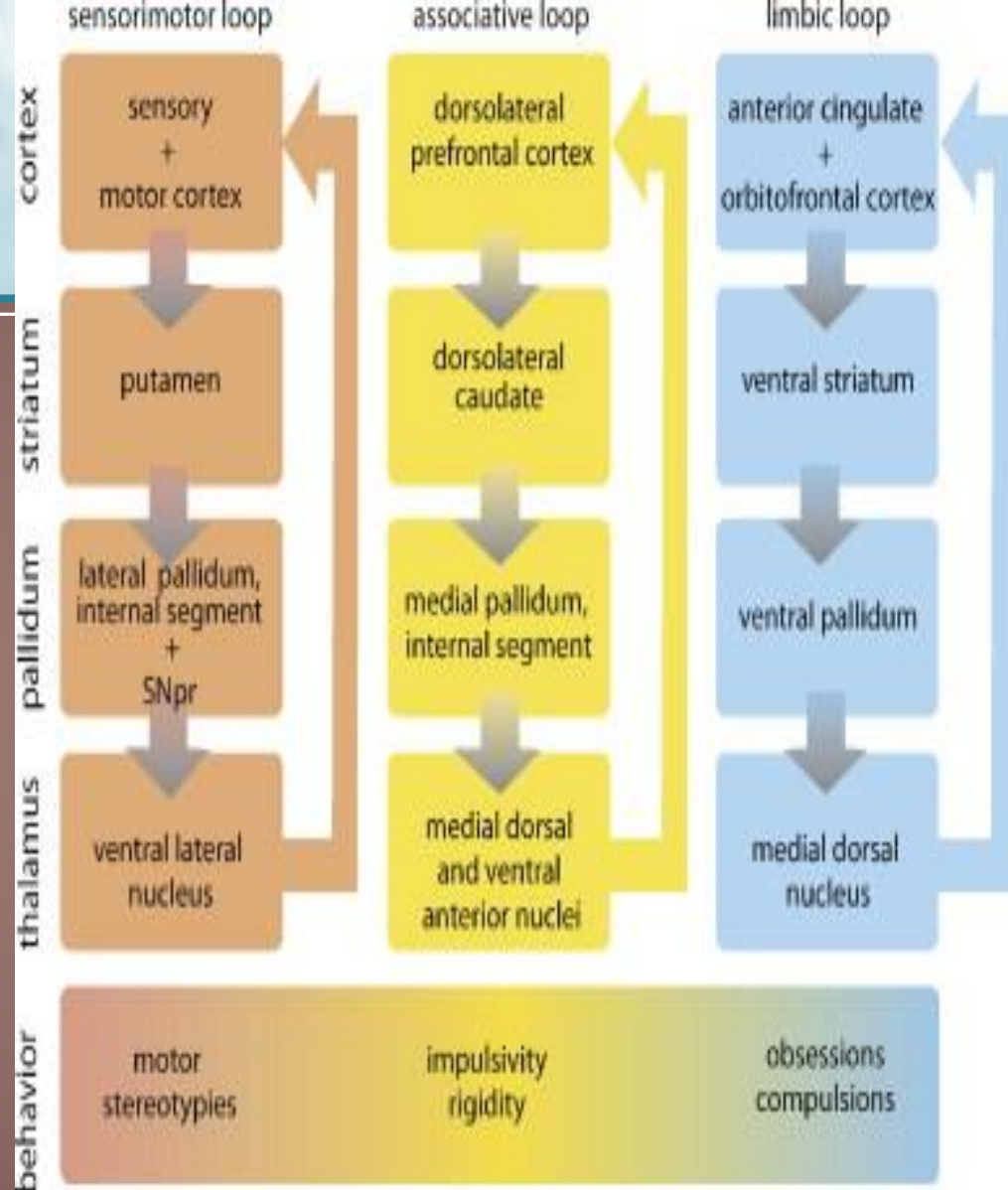
OCD: Etiology

- There is growing evidence that biological factors are a primary contributor to OCD as well as environmental influences/habituated responses.
- The fact that individuals with OCD respond to drugs that affect the neurotransmitter serotonin seems to *suggest that* the disorder may have a neurobiological basis.
- Research also suggests that OCD seems to have a significant genetic contribution, with genetic links to both ADHD and Tourette's disorder.

OCD: Etiology

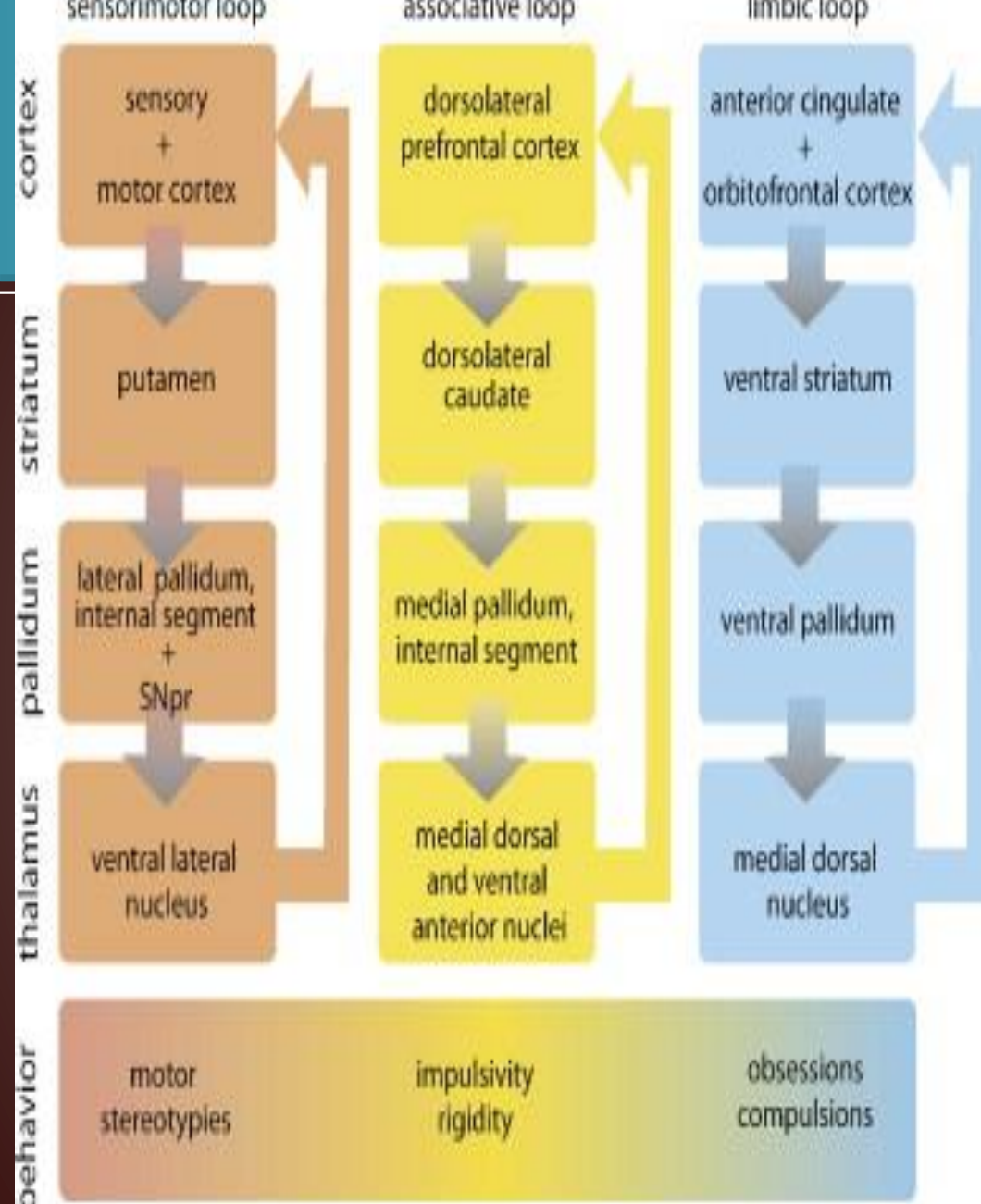
- Recent research has also shown that OCD symptoms may develop or worsen after a strep infection.
- In these instances, the child may develop OCD with no previous family history.
- MRI studies have suggested that individuals with obsessive-compulsive disorder have significantly less white matter than normal control subjects.
- This may suggest a generalized brain abnormality in OCD

1. **Sensorimotor loop** is primarily involved in **abnormal stereotypical motor behavior**: continuously repeating identical movements without pursuing a goal
2. **Associative loop** is likely to be associated with **inappropriate repetition of a goal**, expressed in a relatively varied behavioral repertoire (as in obsessive–compulsive behavior).



~Parallel corticostriatal macro-circuits with their main input, relay and output regions.

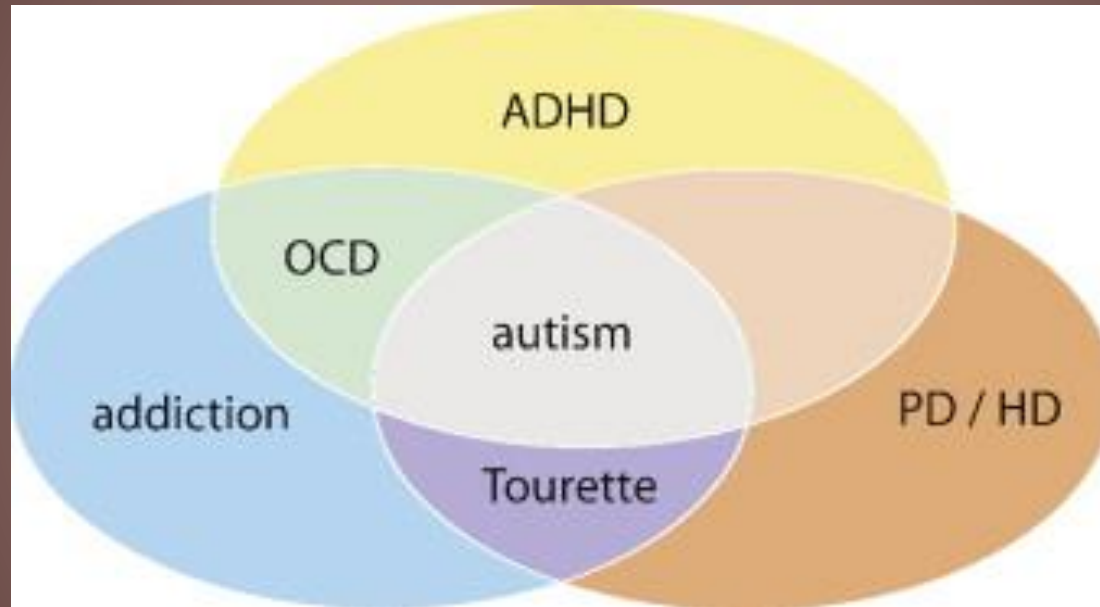
~Abnormal repetition of behavior can result from *damage to any of the corticostriatal circuits*, where the *exact location of the disruption (i.e. which loop is involved)* determines what type of repetitive behavior is seen.



3. Limbic loops (lateral orbital loop and anterior cingulate loop) are implicated in motivational aspects of behavioral control, including impulsive behavior (difficulty in suppressing behavior even when consequences are negative); response to reward; and obsessive and compulsive behavior (including compulsive drug-taking). (SNpr = substantia nigra pars reticulata).

Parallel corticostriatal macro-circuits with their main input, relay and output regions. ~Abnormal repetition of behavior can result from damage to any of the corticostriatal circuits, where the exact location of the disruption (i.e. which loop is involved) determines what type of repetitive behavior is seen.

OCD: Comorbidity

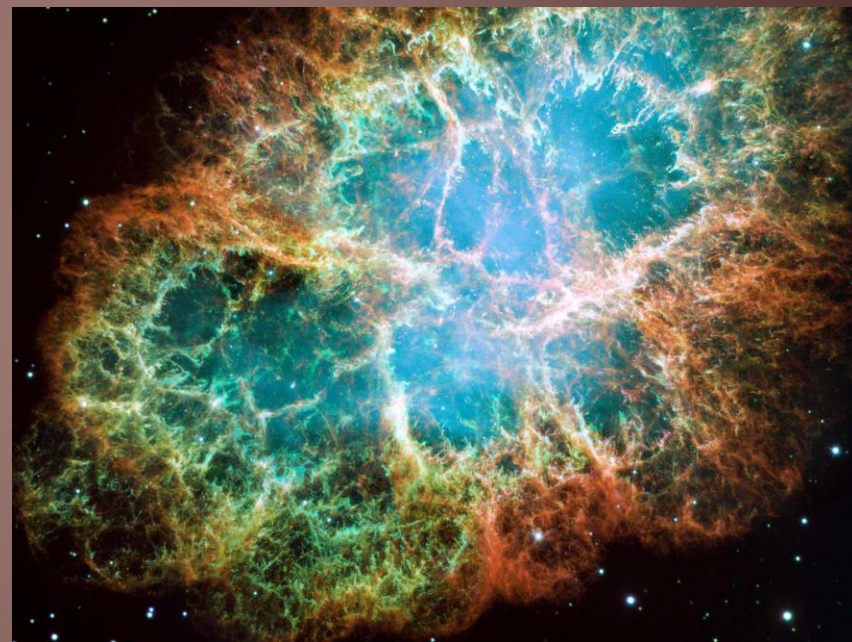


Schematic representation of how behavior resulting from problems in one of the three macro-circuits (sensorimotor, associative or limbic) may group together in symptom clusters as seen in various psychiatric and neurological disorders.

(ADHD = attention deficit hyperactivity disorder; OCD = obsessive–compulsive disorder; PD = Parkinson's disease; HD = Huntington's disease).

Comorbidities- the Rule rather than the exception

- Depression,
- Other anxiety disorders
- Attention deficit hyperactive disorder,
- Tourette's and Tic disorders
- Trichotillomania (the repeated urge to pull out scalp hair, eyelashes, eyebrows or other body hair),
- Co-existing disorders can make OCD more difficult both to diagnose and to treat anxiety



- More severe the OCD more likely to find a comorbid disorder

DSM5 Chapter on OCD & Related Disorders

- Evidence disorders are related to one another in terms of a range of diagnostic validators
 - Clinical utility of grouping these disorders in the same chapter.
- New disorders:
- hoarding disorder, excoriation (skin-picking) disorder
 - substance-/medication-induced obsessive-compulsive and related disorder
 - obsessive-compulsive and related disorder due to another medical condition

DSM5 Chapter on OCD & Related Disorders



- DSM-IV diagnosis of trichotillomania is now termed trichotillomania (hair-pulling disorder)
- Moved from DSM-IV of impulse-control disorders not elsewhere classified to
- Obsessive-compulsive and related disorders in DSM-5.

Specifiers for Obsessive-Compulsive and Related Disorders

- “With poor insight” refined in DSM-5
- Allows a distinction between individuals with good or fair insight, poor insight, and “absent insight/delusional” obsessive-compulsive disorder beliefs (i.e., complete conviction that obsessive-compulsive disorder beliefs are true).

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Obsessive-Compulsive Disorder

DSM 5 Criteria

DSM 5 Criteria

A. Either obsessions or compulsions:

Obsessions as defined by (1), (2), (3), and (4):

1. Recurrent and persistent thoughts, impulses, or images that are experienced, at some time during the disturbance, as intrusive and inappropriate and that cause marked anxiety or distress
2. The thoughts, impulses, or images are not simply excessive worries about real-life problems
3. The person attempts to ignore or suppress such thoughts, impulses, or images, or to neutralize them with some other thought or action
4. The person recognizes that the obsessional thoughts, impulses, or images are a product of his or her own mind (not imposed from without as in thought insertion)

Obsessive-Compulsive Disorder

DSM Criteria

Compulsions as defined by (1) and (2):

1. Repetitive behaviors (e.g., hand washing, ordering, checking) or mental acts (e.g., praying, counting, repeating words silently) that the person feels driven to perform in response to an obsession, or according to rules that must be applied rigidly
2. The behaviors or mental acts are aimed at preventing or reducing distress or preventing some dreaded event or situation; however, these behaviors or mental acts either are not connected in a realistic way with what they are designed to neutralize or prevent or are clearly excessive

Obsessive-Compulsive Disorder

DSM 5 Criteria

- B. At some point during the course of the disorder, the person has recognized that the obsessions or compulsions are excessive or unreasonable. Note: This does not apply to children.
- C. The obsessions or compulsions cause marked distress, are time consuming (take more than 1 hour a day), or significantly interfere with the person's normal routine, occupational (or academic) functioning, or usual social activities or relationships.
- D. If another Axis I disorder is present, the content of the obsessions or compulsions is not restricted to it.
- E. The disturbance is not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition

Common Obsessions and Compulsions

- Obsessions

- Contamination
- Harm to self or others
- Need for symmetry/order
- Religious or moral concerns
- Sexual or aggressive
- Lucky or unlucky numbers

- Compulsions

- Cleaning
- Checking, counting, repeating
- Ordering, straightening
- Praying, confessing, reassurance seeking
- Touching, tapping, or rubbing
- Hoarding

Case Example

Ashley, 26, mild I/DD reports that each time she goes to the bathroom, she has to imagine the number 12 on a clock and say the words "good luck" to herself.

- She reports that she can't stop thinking about the words "good luck." If she tries to stop herself from thinking about these words, she becomes very anxious and worries that she'll have a heart attack.
- At work, she is often frozen at her post, unable to respond. She worries that any decision she makes will result in something dreadful happening to her parents.
- Before going to sleep, she closes the bedroom door four times, turns the lights on and off four times and looks put the window and under her bed twelve times.

OCD: Treatment

- Not Specific to I/DD but could apply to I/DD
- Children with OCD are most commonly treated with a combination of psychotherapy and medication.
- The most common form of psychotherapeutic treatment is behavioral in nature and often takes the form of exposure and response prevention.
- With this approach, the patient is encouraged to **confront the feared object** or idea, either directly or via imagery.
- At the same time he/she is strongly encouraged to **refrain from engaging in compulsive behavior**.

Nature of Response Prevention

- Compulsive hand washer encouraged to touch an object they believe to be contaminated
- Avoid washing until the anxiety that has been elicited has diminished.
- Treatment step-by-step basis, therapy guided by patient's ability to tolerate the anxiety and control compulsive acts.
- Treatment progresses, patients gradually experience less anxiety from obsessive thoughts and are able to resist the compulsive urges.
- While there have been more studies with adults than children, studies of response prevention have found it to be quite effective for the those who complete therapy.

Response Prevention: A Case Illustration

23 yr old Sam with mild I/DD whose ritualistic behavior and obsessional checking severely restricted his every day activities (had some form of these since about 8 yrs old).

- Had to fluff pillows 3 times before undressing at night.
- Bed covers had to be placed so that the fringes only just touched the floor all the way around,
- At night, after removing his shoes, he banged them them on the floor upside down – the right side up three times and then placed them parallel under the bed,
- He went to the toilet 3 times before going to bed,
- Woke up at night to carry out these same rituals.

Response Prevention: Case Illustration

- Before carrying out each of these rituals he had to sing a specific nursery rhyme.
- These behaviors occurred every day and consumed a great deal of her time, making it impossible for her to engage in other activities.

Response Prevention: Approach to Treatment

- In treatment, parents and other caregivers were encouraged **not to reinforce** any compulsive behavior.
- Response prevention involved working with the Sam, his parents and arranging for him to be **prevented** from engaging in any of his ritualistic behaviors more than one time.
- This was followed by developing a **graded** series of situations that tended to elicit compulsive behavior.
- These were graded in terms of their “upset value” for Sam.

Response Prevention: Approach to Treatment

- These situations were presented in graded order, beginning with the mildest situation first.
- They then moved on to those where she might become very upset if she could not carry out her compulsions.
- In each situation, parents prevented her from carrying out the compulsive behavior –
- Hence the term “Response Prevention”.

Response Prevention: Outcome

- Procedures were quite successful.
- Symptoms disappeared after 2 weeks of treatment and limited recurrence of compulsive behavior at 1-year follow-up.
- Extinction is probably largely responsible for the decrease in compulsive behavior and the reduction in anxiety associated with this procedure.
- While seemingly effective for dealing with compulsions, it may be more difficult to apply it to obsessional behavior.

Behavioral Treatment

- There is evidence that the effects of behavior therapy endure after treatment has ended.
- For example, an early review of outcome studies by Foa & Kozak (1996) found that, of 300+ patients treated by exposure and response prevention, approximately 76 % showed clinically significant relief from symptoms 3 months to 6 years after treatment.
- Studies have also found that incorporating follow-up sessions after the completion of therapy contributes to the maintenance of treatment effects (Hiss, Foa, and Kozak, 1994).

Cognitive Behavioral Treatment

- Cognitive behavior therapy involves a structured approach for teaching family members/caregivers how to respond to symptoms.
- Major elements of CBT are exposure and response prevention.
- Another major element is teaching objective thinking strategies.
- Here the individual (mild I/DD) is trained to identify and correct anxiety provoking cognitions.

Cognitive Behavioral Treatment

- Here these strategies are designed to provide children with objective ways to “talk back” to anxiety provoking obsessions that relate to compulsive behavior.
- A major focus is on helping the adult reframe their thoughts and learn coping statements to deal with the cognitive aspects of this anxiety-related disorder.

OCD: Drug Treatments

- Clinical trials have shown that drugs that impact on serotonin can significantly decrease OCD symptoms.
- Examples of these SRIs include the following;
 - clomipramine (Anafranil)
 - fluoxetine (Prozac),
 - fluvoxamine (Luvox),
 - Paroxetine (Paxil)
 - sertraline (Zoloft).
- Studies have shown that more than 3/4 of patients are helped by these medications to some degree.
- In more than 1/2, medications relieve symptoms by diminishing the frequency and intensity of the obsessions and compulsions.
- Side effects can be an issue (Weight gain, dry mouth, nausea, diarrhea)

OCD Treatment

- Antibiotic therapy can also be useful in cases where OCD is linked to streptococcal infection.
- Again, it should be emphasized that the most effective treatment is likely to be one that involves both pharmacological and behavioral approaches to intervention.

N-Acetylcysteine (NAC)

- Selective serotonin reuptake inhibitors (SSRIs) are effective for obsessive-compulsive disorder (OCD)
- Many patients fail to respond adequately
- Few evidence-based second-step options (largely, augmentation with antipsychotics).
- Investigators in Iran randomized 48 patients with treatment-refractory OCD (Yale-Brown Obsessive Compulsive Scale [Y-BOCS] scores, ≥ 16 after 12 weeks of SSRI or clomipramine) to 12 weeks of continued antidepressant plus the glutamatergic modulator N-acetylcysteine (NAC; 600–2400 mg/day) or placebo.

N-Acetylcysteine for Refractory OCD

N-acetylcysteine add-on treatment in refractory obsessive-compulsive disorder: A randomized, double-blind, placebo-controlled trial.

Afshar H et al. J Clin Psychopharmacol 2012 Dec; 32:797.

NAC-

1. Derivative of cysteine
2. With glutamate-modulating properties,
3. Provides modest benefits to patients who are symptomatic after an initial antidepressant trial

Results

- Response - $\geq 35\%$ reduction in Y-BOCS score) was significantly greater with NAC (53%) than placebo (15%).
- NAC was well tolerated, with modest adverse effects of diarrhea and nausea/vomiting in 1/3 of patients.

Findings

- Findings are consistent with results from multiple studies implicating glutamate in the pathophysiology of OCD via cortico-striato-thalamo-cortical circuitry
- Previous small randomized controlled trials showing efficacy of N-acetylcysteine in related OCD-spectrum conditions such as pathological gambling and trichotillomania.
- The low placebo response rate is consistent with treatment resistance and validates the treatment-refractory nature of the studied population.

What is Life Like for Children or Adults Who Have OCD?

- OCD makes daily life very difficult and stressful for individuals and caregivers of those with OCD
- In the morning, they feel they *must* do their rituals right, or the rest of the day will not go well.
- In the evenings, they must finish all of their compulsive rituals before they go to bed.
- Some individuals even stay up late because of their OCD, and are often exhausted the following day.

Resources - Web-based

1. Anxiety Disorders Association of America, www.adaa.org
1. US Department of Health,
<http://mentalhealth.samhsa.gov/publications/allpubs/CA-0007/default.asp>
1. School Psychiatry www.massgeneral.org/schoolpsychiatry/
1. American Association of Child and Adolescent Psychiatry www.aacap.org
2. Intellectualdisability.info
3. Deb, S., Thomas, M. & Bright, C. (2001). Mental disorder in adults with intellectual disability. 1: Prevalence of functional psychiatric illness among a community-based population aged between 16 and 64 years. *Journal of Intellectual Disability Research*, 45(6), 495-505.

