Taming the OCD Monster
Tips & Tricks for Living Sanely with OCD

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FAA Family Resource Meeting

Presented by: Gwennyth Palafox, Ph.D.
What is Obsessive Compulsive Disorder (OCD)?

- Is an anxiety disorder.
- OCD is a disorder of both the brain and behavior.
- Obsessions are the unwanted thoughts, images, or impulses that happen repeatedly and feel outside of a person’s control.
- Compulsions are the repetitive behaviors or thoughts that a person uses to “neutralize” or “counteract” the obsessive thought. Can also include avoidance of situations that trigger obsessions.
OCD is not...

- An obsessive personality trait.
- When someone likes things to be neat, tidy, and/or orderly.
- A routine, a religious practice, or practicing a skill repeatedly.
- Being “obsessed” with a (thing) for a time being while still being able to engage in everyday life.
- A special interest.
OCD is...

- Disturbing
- Unwanted
- Rigid and rule-bound
- Time consuming
- Persistent
- Extremely unproductive
- Aware that it’s irrational
- Debilitating
Common Obsessions

- Contamination (body fluids, germs/disease, dirt, household chemicals, environmental contaminants).
- Perfectionism (exactness, remembering, forgetting important information, inability to discard items, fear of losing items).
- Unwanted Sexual Thoughts (forbidden or perverse sexual thoughts or images, obsession involving children, aggressive sexual behaviors towards others).
Common Obsessions

- Losing Control (fear of acting on an impulse to harm oneself or others, violent or horrific images in one’s mind, fear of stealing, fear of blurting out insults/offensive language).
- Harm (fear of harming others because of carelessness, fear of being responsible for a crime/accident).
Common Obsessions

- Religious (offending God, blasphemy, morality).
- Other (getting a physical illness or disease, superstitions).
Traditional OCD Can Look Like

- Repetitive hand washing
- Obsessing about getting hurt
- Obsessing about getting sick
- Fear of contamination by germs
- Arranging objects in specific patterns
- Used to include hoarding (now a separate diagnosis)
Is it OCD?

- Is an intrusive and unwanted thought (obsession) present?
- Is a repetitive behavior (used to neutralize thought) present?
- Is the behavior interrupting daily life? If yes, how much so?
- Is it causing a significant amount of distress?
- Can medication or substance use be the cause?
- Is not due to a Self-Stimulatory Behavior (SSB).
OCD vs. ASD

- In OCD, an unwanted thought/image/trigger drives a compulsive behavior in order to reduce anxiety or distress that comes along with the intrusive thought.

- In ASD, SSBs are not driven by unwanted thoughts/images/triggers.

- In ASD, a special interest (engaging in it) brings pleasure, not distress.
OCD and ASD

- Up to 40% of individuals with ASD are also diagnosed with an anxiety disorder (percentage increases with aging).
- Up to 17% of individuals with ASD are diagnosed with OCD by the time they are 18 years old.
- It’s only helpful to differentiate OCD and ASD if it directs treatment (there is a difference), intervention, or supports.
- Most common ASD + OCD example:
  - Needing to gain access to a tangible. If denied, tantrums and aggression quickly follow (desire is insatiable).
OCD Treatment

- OCD is very difficult to treat, but there is hope to gain control.
- Most effectively treated with behavioral therapy, cognitive-behavioral therapy (CBT), and medication. There is a difference between behavior therapy and cognitive behavior therapy.
- Robust OCD treatment includes cognitive therapy, exposure therapy, and the development of coping skills.
- Most common CBT treatment/framework is Exposure and Response/Ritual Prevention (ERP).
- CBT plus medication are considered “first line” treatments.
Exposure and Response/Ritual Prevention (ERP)

- Needs to be done by a trained therapist within a structure, routine/regular schedule, and monitoring.
- Often tried by ABA providers without proper training to build distress tolerance and emotional regulation (this can be dangerous and damaging).
- The general idea? Gradually expose trigger while helping individual adaptively tolerate the anxiety associated with not performing the compulsion/ritual.
Tips for Taming the Monster

- Get professional help (one who knows both ASD and OCD)! The best intentions cannot compensate for training and expertise.
- Treatment for discrete OCD is different than OCD + ASD.
- Set expectations accordingly. When set too high or too low, learned helplessness and reduced self-esteem can set in and negatively impact treatment. It also leads to mistrust of professionals and future attempts at treatment.
- There is no “cure” for OCD. It is likely that an individual with OCD will need to manage symptoms for their entire life (on some level).
Tips for Taming the Monster

- Do not try extinction (ignoring). Trying to ignore intrusive thoughts does not work. This causes more stress and anxiety. Without strong emotional resourcing, this causes disasters which can lead to serious problems (sometimes legal).
- Use brain science...shift attention.
- Go for changing the way OCD looks instead of eliminating it completely. Reduce it’s brain strength. This is a more humane way of managing day-to-day life while “chipping away” at OCD.
Tips for Taming the Monster

- Pick your battles. Don’t fight them all, but pick one!
- Do not let OCD unattended. It will gather momentum, synapses will get strengthened, and it will interfere with life.
- Be a warrior about teaching adaptive coping, distress tolerance, and emotional regulation. Use everyday life events as much as you can for generalization and meaning.
- Differentiate between danger and discomfort.
Tips for Taming the Monster

- Calm the “fight/flight/freeze” response by breathing.
- Try to characterize OCD as being a separate entity. Compartmentalize and contain.
- Combat/challenge irrational thoughts as much as the individual will tolerate.
- Map out behavioral chains and insert “choose your own adventures” to promote empowerment.
I have OCD but OCD does not have me.
Tips for Taming the Monster

- Try to differentiate what is OCD and what is ASD. Many times, it won’t be clear cut, but thinking about this more deeply will help with directing intervention.
- Work on increasing self-awareness/state identification to identify when a thought is obsessive.
- Focus on improving self-care (eating, sleep, exercise).
- Focus on stress management (breathing).
Tips for Taming the Monster

- Provide psychoeducation (if the individual can understand/comprehend).
  - Anxiety vs. Fear
  - Flight-Fight-Freeze Response (purpose)
  - Want to get “front brained” if possible
  - Purpose of breathing (shift from sympathetic [fight-flight] to parasympathetic [rest])
Tips for Taming the Monster

- Co-Regulate
  - By the amount you say (add to the sensory environment)
  - By calm behavior
  - By deep breathing (diaphragmatic)

- Coping Skills
  - Breathing retraining
  - Progressive Muscle Relaxation
Tips for Taming the Monster

- If able, promote:
  - Mindfulness (here and now without judgment).
  - Acceptance (of self and others).
  - Interpersonal skills (social skills, assertiveness).
  - Emotional regulation (identifying all emotions and learning how to manage them).
  - Distress tolerance (tolerating and dealing with overwhelming emotions, thoughts, or situations).
“You are the sky. Everything else — it’s just the weather.”

— Pema Chödrön
Real-Time Application

- Get out a piece of paper.
  1. Describe fear and anxiety (feelings, body, and thoughts).
  2. Identify triggers.
  3. Use numerical scale to describe intensity when triggered.
  4. What works to calm?
  5. What doesn’t work?
  6. What are your child’s strengths?
     Weaknesses/barriers?
When Outpatient Treatments Don’t Work

- Make sure that you received sound outpatient treatment.
- Sometimes, OCD can be so debilitating, more intensive care is needed.
- From least to most supportive:
  - Intensive Outpatient (several days per week of therapy).
  - Day Programs (participate in a full day of treatment five days per week @ a mental health treatment center).
  - Partial Hospitalization (participate in a full day of treatment five days per week @ a hospital).
  - Residential (living voluntarily in an unlocked treatment center).
  - Inpatient (most intense with participation in a locked treatment center). This is both voluntary and involuntary.
Resources

- International OCD Foundation (www.iocdf.org)
- Anxiety and Depression Association of America (www.adaa.org)
- Autism Speaks (www.autismspeaks.org)
Resources

- Helping Your Anxious Child: A Step-by-Step Guide for Parents (Rapee et al.)
- If Your Adolescent Has an Anxiety Disorder: An Essential Resource for Parents (Foa and Andrews)