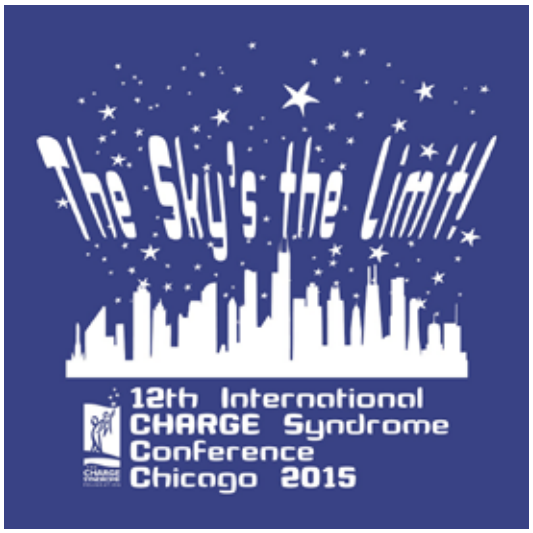


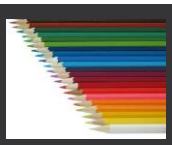
Saturday, August 1, 2015
Breakout Session #34: 1:00 - 2:00pm
Schaumburg East

Why Does My Child Do That? Explanation of and Strategies for Dealing with Compulsive Behaviors and OCD in CHARGE Syndrome

Nancy Salem-Hartshorne, Ph.D.
Delta College

Presenter Information:
Nancy Salem-Hartshorne, Ph.D. is Assistant Professor of Psychology at Delta College, and a School Psychologist. She has authored articles and book chapters about developmental outcomes for individuals with CHARGE syndrome. Her son, Jacob, 25, has CHARGE syndrome, and lives in his own home. Nancy is an advocate for individuals with disabilities, teamwork, thorough planning, and forward thinking for quality life outcomes for all individuals.

Presentation Abstract:
All of us have repetitive or compulsive behaviors. All of us have hobbies. But when we see these obsessions and compulsions in our children with CHARGE, they can look odd or disturbing, or may prevent them from accomplishing all that they can, and we worry. Anxiety is the key! Dr. Hartshorne will talk about strategies to address anxiety and OCD-like behaviors in children with CHARGE syndrome.



Why Does My Child Do That?

Compulsive Behaviors and OCD in CHARGE Syndrome

- **DSM-5 Diagnostic Criteria for Obsessive-Compulsive Disorder (300.3)**

Obsessions

Recurrent and persistent thoughts, urges, or impulses that are experienced, at some time during the disturbance, as intrusive and unwanted, and that in most individuals cause marked anxiety or distress. (Typically irrational fears.)

The individual attempts to ignore or suppress such thoughts, urges, or images, or to neutralize them with some other thought or action (i.e., by performing a compulsion).

Compulsions

Repetitive behaviors (e.g., hand washing, ordering, checking) or mental acts (e.g., praying, counting, repeating words silently) that the individual feels driven to perform in response to an obsession or according to rules that must be applied rigidly.

The behaviors or mental acts are aimed at preventing or reducing anxiety or distress, or preventing some dreaded event or situation; however, these behaviors or mental acts are not connected in a realistic way with what they are designed to neutralize or prevent, or are clearly excessive.

Obsessions: Disturbing, Intrusive Thoughts or Fears (Irrational)

Typical Obsessive Fears/Thoughts
Harm to property: burglars, fire, electrical fire, losing something important
Contamination: deadly disease, germs crawling into skin
Harm to a loved one or fear you will harm someone
Magical thoughts
A number or day is good or bad
Step on a crack…
Hearing or saying bad words will produce bad results
Making a religious mistake/sinning will result in going to hell
Fear of not having everything "just right"

Compulsions: Behaviors/Actions to alleviate worry over the irrational thoughts

Obsession	Typical Compulsions
Harm to property	Check locks, oven, hoard objects
Contamination	Wash hands
Harm to loved one	Text or call repeatedly to check
Magical thoughts	Avoid cracks
Numbers	Avoid using or ending on that number
Bad words	Fix the bad word by saying something else
Religious mistake	Repetitive and excessive prayer
Everything just right	Neatness, orderly, line up, make symmetrical

OCD is an ANXIETY disorder

- You feel stress or anxiety
- You perform compulsive acts to relieve it
- You can try to stop your behavior, but it will only increase anxiety

- A pattern that has developed through reinforcement.
- Relief after compulsion felt as a temporary reward.
- You want that reward again, so you'll do the compulsive act again.
- If it's in the way of your life, it's considered a disorder.

Example: Nancy at age 16

- Obsession over sin/fear of hell: Excessive, repetitive prayer
- Fear of not waking up: Staying up all night
- Rigidly applying rules: counting: 7, 15, 17, 25, 37; Saying/touching things 7 times; don't step on cracks; unwind when you turn around
- Fear of darkness/night: Sit outside and watch sunset until gone, panicking
- Fear of sin/hell: repeating religious swear words heard under breath with alternatives (gosh, heck, darn)
- This was utterly debilitating. It took ALL of my time to attend to these things.

I suggest to you……..

- Most individuals with CHARGE syndrome don't have *true* OCD.
- Someone with true OCD has irrational thoughts leading to irrational anxiety.
- The treatment involves exposure to the irrational thought, and prevention of the compulsive response.

- Individuals with CHARGE have TRUE circumstances that lead to UNDERSTANDABLE anxiety!

OCD-like behaviors seen in CHARGE

- **My son Jacob uses "Everything must be just right."**
  - Ordering/Lining up/Making symmetrical
  - Placing/moving to correct place
  - Light switches
  - Doors closed/open
  - Handing cup to caregivers when he sees it
- I've seen many individuals with CHARGE use this method.
- **Other things reported or seen:**
  - Repetitive question-asking: "What color is your car?" "What color is your house?"
  - Stuffing things into slots—especially into places from which they are difficult to retrieve.
  - Repetitive, idiosyncratic behaviors: Hand movements, tics
  - Rigid inability to switch activities
  - All-consuming focus on one idea, activity, or item, to the point that it's not just a hobby/intense interest—Keeping in mind that we ALL have interests/hobbies!
  - What else?

Prevalence of OCD-Like Behaviors in CHARGE

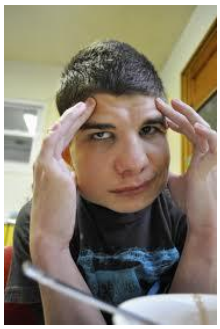
Salem-Hartshorne, N., Blake, K., (in process): 53 Participants. 33 male. Ages 13+

- 49.1% OCD-Like Behaviors
- 45.3% Anxiety

"A lot of what looks like OCD in CHARGE is really just a reaction to having multi-sensory impairments"– D. Brown 2015

These are actually very creative responses to abnormal, anxiety-provoking circumstances.

Caveat: Someone with CHARGE syndrome could possibly also develop typical OCD, but this is not the norm.



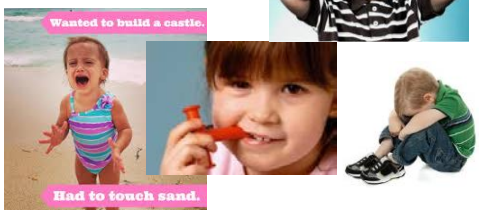
What could our kids possibly have to be anxious about?

The following things may produce real and understandable anxiety for individuals with CHARGE syndrome. These triggers may cause the fear and anxiety, which then produce compulsive behavior.

1. PAIN

It doesn't often come with a big sign

2. Sensory overload or underload issues



How about just plain boredom?

- When you're waiting/bored, do you:
  - Tap a pencil
  - Wag your legs when sitting
  - Play with your hair
  - Bite your nails
  - (Now that we have smartphones, we do other things as well).

These are all ways of keeping ourselves occupied, or of keeping ourselves aroused and alert.

What do your kids do that look like these, but may not seem as "normal"?

How about checking?

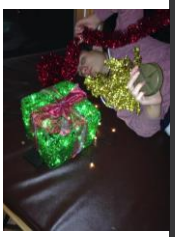
"Checking" is an OCD compulsion. For example, checking to see if the oven has been turned off….seven times….

David Brown's Thoughts:

If you don't have all of the sensory information you need to be reassured, if you never get complete information about your surroundings, if your environment is chaotic and constantly changing, these behaviors make a sort of sense:

- Tapping things with your hand
- Running your hand along the edge of a table
- Arranging items in regular rows or stacks
- Confirming where things are
- Constantly checking if things have changed (has the chair moved, etc?)

If small things can change, then it's scary to think that bigger things in the world can change as well. If I can control the small things, it helps with the anxiety over the bigger things.

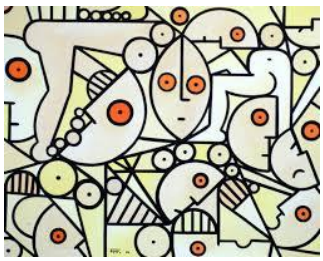


Sleep

- Sleep and anxiety are related in the general population
  - Fuller, Waters, Binks, & Anderson (1997) found a strong association between high anxiety/worry and clinically significant sleep disturbance
- Salem-Hartshorne & Blake (in process) found almost 60% had sleep problems in adolescent/adult CHARGE sample.
- If there's any way to increase sleep quality, anxiety may decrease.
- Also, reducing anxiety by increasing predictability, helping with sensory issues, and alleviating pain may help sleep quality.

3. Stress

- Life is chaotic.
- I cannot hear/see/balance/ predict what's going to happen next.
- I want to escape the chaos.



Steps to Help

To do

or

not to do?

Step One:
Figure out the purpose of the behavior

- What is its goal? What function does it serve for the individual?

What looks like an inappropriate goal may be masking something else.

Repetitive questions: "What color is your car, what color is your house?"

- Need for social interaction but not having social skills to initiate true conversations—they know they are supposed to do something. This is what they know how to do.
- Need to do something to organize a chaotic situation with many people around—they are overwhelmed and this is one way to make the situation understandable.
- Need to know more about people to feel safe around them—they are among strangers.

"I want to be a professor…"

Step Two: How urgent is it?

Urgency of Intervention Questions (D. Brown, 2015)

1. Is this a behavior that just bugs you personally, so that it can be accepted and ignored?
2. Is this a behavior that seems to help the child to function in a positive way, so that it can be accepted and ignored?
3. Is this a behavior that seems to help the child to function in a positive way, but could be reduced, or replaced by another more appropriate behavior?
4. Is this a behavior that is undesirable and really needs to be reduced or replaced over time?
5. Is this a behavior that needs to be prevented immediately?
6. Finally, how much can we improve things by changing our behavior and the environment that the child is in, rather than directly trying to change them?

Step Three: Intervention

Pain

Communication of pain may devolve until you get someone's attention, especially if your communication skills are limited or you have difficulty understanding what's happening to you when you are in pain.

Level 1. Avoiding work, putting my head down, or lying on the floor

Level 2. Crying, whining, complaining, acting out

Level 3. Hitting, biting, pulling hair

- This person is communicating, but we aren't understanding. So they change their communication mode until we notice!
- There is a need to help them find a way to more appropriately identify and communicate pain.
- For some, pain behaviors, although worrisome, can be quite helpful.
  - When Jacob blows raspberries repeatedly, we know it's gas pain or cramping
  - When Jacob digs things into his neck, we know it's his ears bothering him
  - He doesn't have other ways (yet) to tell us these things.

CHARGE Non-Vocal Pain Assessment

(Stratton, 2012) (Excerpt)

ACTIVITY/CHALLENGING BEHAVIORS				
Less active or quiet	0	1	2	3
Restless/agitated	0	1	2	3
Self-injurious behaviors				
(Biting self, banging/hitting head)	0	1	2	3
Aggressive				
(e.g. hitting others, throwing objects)	0	1	2	3
Acts out/Misbehaves	0	1	2	3
Disturbed sleep	0	1	2	3
Change in eating habits	0	1	2	3
Resists being moved	0	1	2	3
Increase in OCD-like behaviors	0	1	2	3

Sensory Issues

- Sensory Integration (deep pressure, weighted garments, etc., to bring arousal level down)
- Sensory breaks (to bring arousal level up)
- Allow to withdraw when overwhelmed
- Set up a better sensory situation for environment

Boredom

Example: Waiting in a doctor's waiting room or at a meeting or restaurant can bring on all kinds of strange-looking behaviors in Jacob.

- Rocking
- Blowing
- Hand-flapping

Why?

He can't see or hear the TV everyone else is watching
He doesn't have a smart phone. (What did we do without those?)
He needs something to stimulate his brain.

For Jake, sensory toys really help. What would work for you?

Checking

These behaviors may be necessary to alleviate the anxiety brought on by not having full availability of sensory information.

Interventions:

- Allow the behavior, as it serves a clear purpose for the individual
- Make the environment as stable and predictable as possible

Sleep

If sleep and anxiety are related, there are two things that might help:

1. **Improve quality of sleep**
   1. Sleep Hygiene
   2. Pay attention to sensory overload
   3. Melatonin has been used by some to help bring on sleepiness
2. **Reduce anxiety**

Stress/Anxiety: The Key is *Predictability*

(adapted from Tim Hartshorne, 2014)

We like to know what is going on.

- What are we doing right now?
- What are we going to do next?
- What did we just do?

Why use a calendar system?

- Security of knowing what comes next
- Being able to anticipate things – looking forward
- Alert to unexpected changes in routine
- Allows for participation in decisions about events
- Allows for conversation about what has happened
- Provides for a mutually understood topic for dialogues
- Clearly represents the passage of time
- Reduces anxiety about what has, is, and will happen

Imagine waking up and…

- No idea what time it is
- No idea of what will happen today
- No idea how soon something might happen
- No idea of the expectations for what will happen
- Problems detecting the true passage of time
- Will I like it?
- Jacob in the car

- This can cause lots of anxiety!

To start

- The child needs to have a communication system of some kind and a plan for its development
  - Objects
  - Pictures
  - Signs
  - Words
- Activity routines must be in place
  - A calendar makes things more predictable
  - You have to have a predictable schedule
  - Tim Hartshorne's talk after this one will detail ways to do this.

Communication

- Calendars provide an opportunity for conversation around the schedule.
  - What we are doing now
  - What we are doing later
  - What we just did
- Calendar systems also teach what time is!
- Once the individual understands the concept of the calendar, they can make choices within it, and it can be used for all kinds of routines.
- Technology for these types of things is exploding (If-Then Visual Schedule on iPad)

Questions,
Comments,
Concerns,
Bellyaches?