



Family Accommodation in Pediatric OCD

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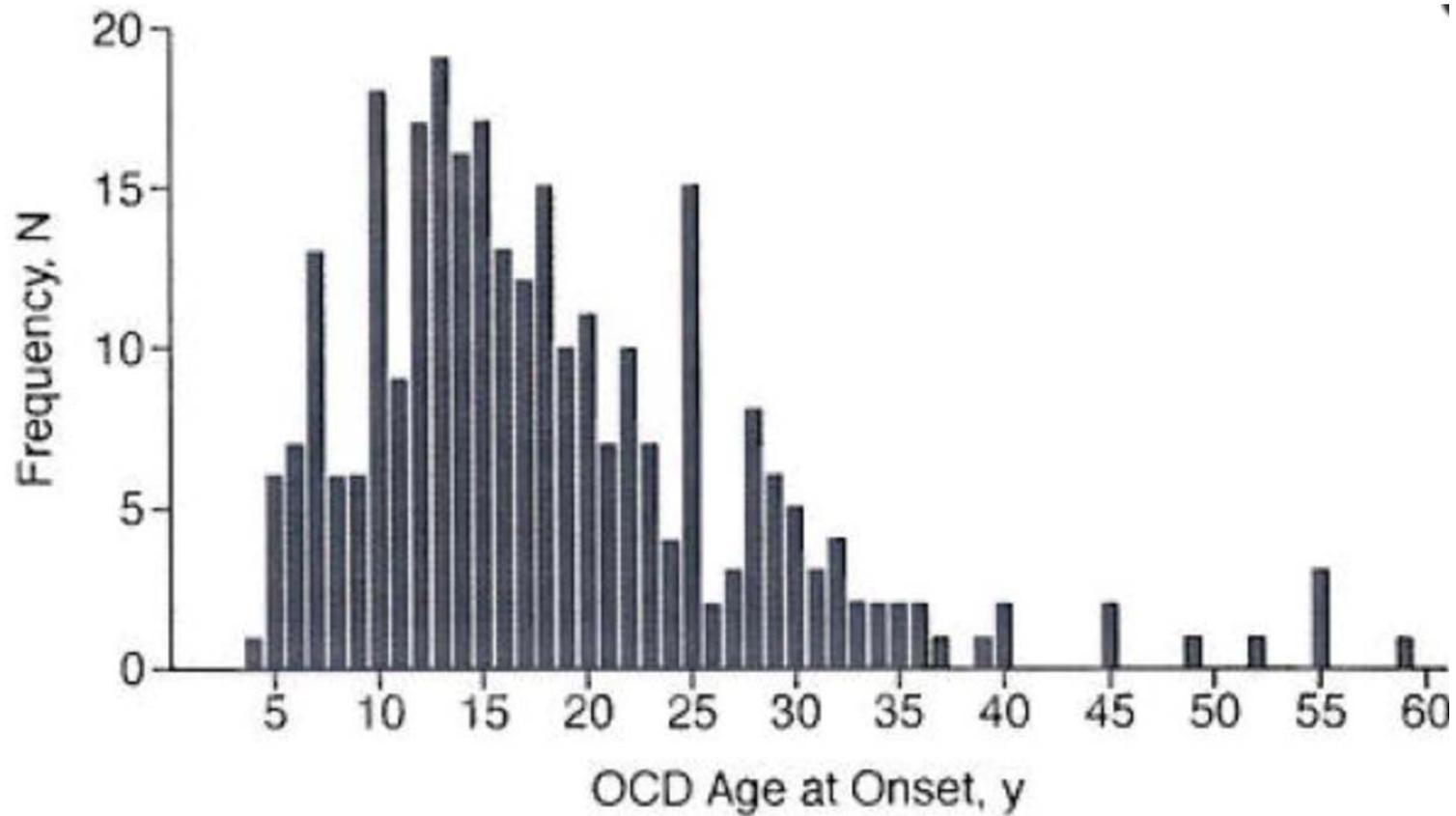
OCD in Children and Adolescents



- Prevalence rates in childhood of 1-2%
- At least half of adults report that their symptoms of OCD began in childhood (Janowitz et al, 2009; Rasmussen & Eisen, 2002)
- Bimodal distribution of age of onset with first peak at age 11, and second peak in early adulthood (Delorme et al, 2005)
- Male preponderance in childhood OCD diagnosis
 - Boys are also diagnosed at younger ages
 - Mean age of onset for pediatric OCD between 9 and 11 years in boys, and between 11 and 13 years in girls (Kessler et al, 2005)



From Pinto et al., 2006. The Brown Longitudinal Obsessive-Compulsive Study: Clinical Features and Symptoms of the Sample at Intake. *J Clin Psychiatry*. 2006 May; 67(5): 703–711.



Parent Involvement in Treatment



- Literature to support parents learning therapeutic skills to reduce accommodation and reinforce CBT skills
- Can learn disengagement strategies for reducing accommodation
- Parents are aligned with CBT goals and can reinforce them in the home setting
- Can help recognize anxiety/depression symptoms and develop new CBT goals



Parents as Coaches



- Parents should be involved in the vast majority of sessions
 - Learning skills (e.g., CT, ERP, etc.)
- Parents can conduct ERP tasks
 - Therapist should model first and gradually allow parents to take over
- Parents and kids help guide homework



Parent Coaching



- Coaching principles
 - Replace avoidance with approach
 - Small steps
- Be positive and supportive
- Help your child plan and complete exposures
- Learn from hands-on practice
- Exposure to your child's distress
 - Balance pushing vs. accommodating
- Generalize to daily situations
- Behavior Management



Parents engaging in ERP

- Planning exposure:
 - Specific time; Pick an item; Repeat until it no longer causes anxiety
 - Identify and evaluate fear
- During exposure:
 - Emphasize anxiety is decreasing by merely facing fears without rituals
 - Record distress every few minutes
 - Watch for rituals
 - Say “That’s great” when ratings change
 - Continue until anxiety has decreased
- Learning from exposure:
 - “Did your fear come true?”
 - “What happened to your anxiety?”

Parent Coaching



- Keeping kids motivated
 - Internal motivation
 - Rewards
 - Poker chip system
 - Glass beads
 - Consequences
 - Natural





Family Accommodation



Family Accommodation in OCD

Symptom accommodation:

“...actions taken by the family members* to:

- *Acquiesce to the child's demands*
 - e.g., allowing child to miss activities to minimize discomfort
- *Participate in the child's rituals/symptoms*
 - e.g., changing clothes when entering the house, opening doors for child
- *Provide reassurance* to the child
 - e.g., answer questions repeatedly
- *Decrease child's responsibility*
 - e.g., minimize attempts at discipline
- *Assist with or complete tasks for the child*
 - e.g., extra assistance with homework, chores, and so on

(Storch et al., 2010; p. 207-208).

* *Applies to adults and non-family members as well*

Symptom Accommodation in OCD: Why is it problematic?

- Leads to more negative family dynamics (Steketee & Van Noppen, 2003).
- Maintains or worsens OCD symptoms
 - Provides **short-term relief** due to allowing the individual to avoid anxiety or other negative consequences of his/her symptoms
 - *So, they will want more and more accommodation over time*
 - Prevents the individual from experiencing a reduction in anxiety after facing the feared situation without rituals/avoidance → **prevents *habituation***.
 - *They don't learn that they can cope with the anxiety without needing accommodation or other problematic behaviors.*
- **Reduces negative consequences** of an individual's OCD symptoms/behaviors that may impact the individual's motivation for change or involvement in treatment.

Frequency of Symptom Accommodation in OCD

- Most research completed with **parents or family members** of individuals with OCD.
- Most families accommodate!
 - **Approximately 70% or more** (Allsopp & Verduyn, 1990; Merlo et al., 2007).
 - High rates of accommodation also reported with siblings (Barrett, Healy-Farrell, & March, 2004).
- Most frequent types of accommodation (Albert et al., 2010; Peris, Bergman, Langley, Chang, McCracken, & Piacentini, 2008; Stewart et al., 2008; Storch et al., 2009):
 - Providing **reassurance**
 - **Waiting** for rituals to be completed
 - Assisting with **avoidance** of anxiety-provoking stimuli
 - Directly **participating in rituals**

Symptom Accommodation in OCD: Relationships with Patient Variables

- Accommodation related to **OCD symptom severity** in many studies (e.g., Calvocoressi et al., 1995, 1999; Caporino et al., 2012; Flessner, Sapyta, Garcia et al., 2011; Merlo et al., 20009; Storch et al., 2009)
 - ...**but not all** (e.g., Amir et al., 2000 – adult sample).
- Accommodation specifically associated with **contamination symptoms** (Albert et al., 2010; Boeding et al., 2013; Flessner, Sapyta, Garcia et al., 2009; Stewart et al., 2008).
- Among children, **related to parent-rated but not child-rated functional impairment** (Caporino et al., 2012; Storch et al., 2009).
 - With greater severity receive more accommodation and therefore are protected from distress and impairment from child's view whereas parents recognize impairment?
- Accommodation more likely if child has both **OCD and disruptive behavior disorder** (Storch, Lewin et al., 2010) / **externalizing symptoms** (Caporino et al., 2012).

Symptom Accommodation in OCD: Relationships with Family Variables



Accommodation related to...

- Poorer family functioning, greater family stress (Calvocoressi et al., 1995).
 - Ends up consuming increasing amounts of time for the family
 - Leads to unintended changes in the family routine
- Relatives' symptoms of anxiety and depression (Amir, Freshman, & Foa, 2000).
 - Siblings have poorer mental health outcomes



Parental Factors in Outcomes



- Parent psychopathology generally, with parental anxiety, OCD, and child OCD severity related to parental involvement in child's rituals (Peris et al., 2008; Storch, Geffken, Merlo et al., 2007).
 - Parental OCD severity predictor of increased accommodation
- 20% of parents of children with OCD have OCD themselves



Impact of Accommodation on OCD Treatment



- Higher accommodation related to **poorer treatment outcome** among both adult and child studies (Boeding et al., 2013; Chambless & Steketee, 1999; Ferrao et al., 2006; Garcia et al., 2010; Storch, Merlo, Larson et al., 2008).
- In a case controlled study comparing treatment responders to refractory patients, family accommodation one of three variables related to **refractory OCD** (Ferrao et al., 2006; other variables were sexual obsessions and low SES).



Impact of OCD Treatment on Accommodation



- Accommodation decreases following treatment (e.g., Barrett et al. 2004; Ferrao et al., 2006; Merlo et al., 2009)
- Decreases in accommodation during treatment predict outcome even after controlling pre-treatment OCD severity or parent-rated child impairment (Merlo et al., 2009).
- Benefits of family-based CBT for child OCD on reducing accommodation (Freeman, Garcia, Coyne et al., 2008; Freeman, Garcia, Fucci et al., 2003; Storch, Geffken, Merlo et al., 2007).



Why some families accommodate:



- It's easier in the beginning
- You think it is helpful
- It worked with your other children
- It's hard to tolerate your child's anxiety/distress
- You feel guilty or "mean" if you don't accommodate
- You fear your child will feel unloved if you don't accommodate
- You are scared of your child's behavioral response



General Family Accommodations

- Avoidance
 - Allowing child to avoid school, activities, places, objects or persons because of OCD/anxiety
- Change in Routines
 - Changing child's or family's routine due to child's OCD/anxiety
 - One parent now stays with child with OCD/anxiety
 - Family members ride separately to events due to child's rituals or avoidance causing them to be late
 - Changing parental routine to be available to answer teen's calls or texts from school

General Family Accommodations



- Increase in parenting duties
 - Increased household duties
 - Spending time preparing others for child's symptoms
- Reduction in age-appropriate responsibilities
 - No household chores
 - No homework or parent completes large portion
 - Does not have to complete activities of daily living
- Anything to keep child from feeling anxious or upset related to OCD/anxiety



Contamination OCD Accommodations

- Assisting a child in washing rituals
 - Hand washing
 - Completion of shower rituals
- Assisting child to not touch contaminated items
 - Opening doors
 - Turning on light switches
- Not entering child's room or touching objects in room
- Buying or washing items needed to complete rituals

Contamination OCD Accommodations



- Implementing “safe zones”
 - No one is allowed to sit on certain furniture
 - No one can touch child’s clothing, dishes, back pack, etc.
- Not entering child’s room or touching objects in room
 - Preventing siblings from touching items
- Buying or washing items needed to complete rituals
 - Ordering items in bulk so you are sure never to run out



Accommodation with Checking/Repeating

- Allowing child to repeatedly check doors, appliances, etc.
- Making excuses for child's tardiness due to being late with rituals
- Participating in rituals by checking items or repeating for child because they are too exhausted
- Checking to provide certainty
 - Having parent check the closets, electrical items, door locks, etc.

Other OCD Accommodations



- Repeating phrases or actions (scripting)
 - Not providing consequences for physical aggression when parent does not do script correctly
- Getting rid of items in home that make patient feel anxious
- Not allowing people in home
- Buying items needed to complete rituals
- Preparing separate food
- Allowing teen to “confess”



Reassurance: A form of accommodation

- Reassurance seeking involves:
 - A child asking a family member repetitive and frequent questions
 - Asking the same question over and over in order to hear from parent/adult that things will be “okay” or that the parent/adult will give the “right answer”
 - Providing certainty in all situations
- Information seeking vs. reassurance seeking

Information Seeking	Reassurance Seeking
Asks a question once	Repeatedly asks the same question
Asks a question to be informed	Asks questions to feel less anxious
Accepts the answer provided	Responds to the answer by challenging the answerer, arguing, or insisting the answer be repeated or rephrased
Asks people who are qualified to answer the question	Often asks people who are unqualified to answer the question
Asks questions that are unanswerable	Often asks questions that are unanswerable
Seeks the truth	Seeks a desired answer
Accepts relative, qualified or uncertain answers when appropriate	Insists on absolute, definitive answers whether appropriate or not
Pursues only the information necessary to form a conclusion or make a decision	Indefinitely pursues information without ever forming a conclusion or making a decision

Developed at the Anxiety Disorders Center,
St. Louis Behavioral Medicine Institute



Examples of Reassurance Seeking

- Requests for Reassurance
 - “Are you sure you....locked all the doors?”
 - “Daddy will be alright, won’t he?”
 - “I did a bad job.”
 - Calling mom or dad repeatedly from school to make sure they are “okay”.
 - “Do you love me?”

What's the problem with giving reassurance?



- It's a bottomless pit because you can NEVER provide enough reassurance.
- It's a never ending cycle – the more you give reassurance, the more the child wants
- It undermines CBT work because it provides the child with the message that there is actual danger
- IT'S EXHAUSTING!!!



Why should we stop giving reassurance?



- It aligns with the goals of CBT to help reduce the child's anxiety and quits “feeding” the anxiety monster
- It gives the child a sense of independence and competence when they learn to cope with their anxiety
- Families feel less exhausted and frustrated!
- Improves treatment outcomes





Helping Families Reduce Symptom Accommodation



Reducing Accommodation



- Remove accommodation slowly and while apprising the child of changes
- Parents can demonstrate compassion while not accommodating
 - “I know you’d like me to say goodbye ‘just so’ but I’m not going to let OCD boss you OR me around like that.”
- Consider adding accommodation removal to the hierarchy or making a separate one



Family Psychoeducation



- Cognitive restructuring:
 - Information about accommodation and effects on treatment
 - Many parents feel guilty after effects of accommodation are explained
 - Assess how anxiety/depression has impacted the family
 - How has anxiety changed your family routines and dynamics?
 - Imagine life without child's illness controlling your life
 - Consider what your family would look like if you were not "walking on eggshells"
- Motivation for change:
 - How would you spend your time if you were not providing accommodations or giving reassurance?



Stress on Marital Relationships



- Accept that you and your partner may cope differently and may handle your child's OCD differently
- Try to understand your spouse's perspective
- Be a united front with your child and treatment team
- Nurture your relationship
- Participate in counseling if needed



Self-Care

- This is something we have to remind every parent.
- Modeling healthy choices to manage mood/anxiety
 - Airplane oxygen mask example
- When is the last time:
 - You have exercised routinely?
 - Gone on a date with your spouse?
 - Spent time with your friends?
 - Read a book (that has nothing to do with your child)?
- Take time while your child is in treatment to reset your routine and family's routine

Prepare for Change



- Provide anticipatory guidance:
 - Your child will NOT thank you for removing accommodations
 - It is likely that your child will initially get worse when you withdraw accommodations
 - Anger may be expressed from your child that you are not accommodating them
 - “Mom, you don’t love me anymore!”
 - “You’re the meanest parent in the world!”
 - Remain consistent!



Supporting Parents



- Encouragement
 - This is not an easy process!
- Support groups
- Think about the changes that need to happen in context of relationship and long-term outcomes



Reducing Accommodations



- Needs to be in concert with the treatment team and the CBT goals
 - Important that treatment team, parents and adolescent are working together and are in agreement
- Typically, accommodation reduction occurs gradually
- Accommodation reduction through good communication
 - Discuss working as a team to fight illness
 - Separate illness driven behaviors from adolescent



Reducing Accommodations



- At home, practice accommodation reduction
 - For example, do not repeat phrases for your loved one
- Help track ban/stop behaviors – remind them to record ban behaviors
- Do NOT provide mixed messages
- Develop behavioral contingencies to reward desired behaviors



Reducing Accommodations



- Ask your loved one to rate his/her anxiety
 - If anxiety is high this is a cue that it will difficult to communicate effectively
- Feelings cannot always be controlled, but behaviors can
- Have a plan
 - Timely disengagement
 - Don't over talk at moments of high stress for your adolescent
- Process the incident when your loved one is calm
- Be consistent!



Tolerating your loved one's anxiety / depression

- Put on your poker face!
- Be aware of your body language and tone of voice when your child is anxious
- You can be empathetic without being accommodating
 - I know you are feeling anxious, but I want to fight OCD with you...
- Have age-appropriate expectations
- Thought challenge: Anxiety is NOT dangerous.

Reducing Reassurance



- Reducing reassurance is crucial to treatment success
- Include the family members who interact with child often
- Consider including school personnel
- Make a plan involving the clinicians, family and child on how reassurance will be handled going forward
- Follow through on the plan



How To Replace Reassurance?

Reassurance vs. Validation

- **Reassurance:** the act of removing doubt or fear; a verbal or nonverbal action that is done in an attempt **to reduce someone's doubt, fear, or distress** (e.g., anything that artificially reduces anxiety or attempts to **offer certainty** when certainty is not available).
- **Validation:** verbal or nonverbal communication to another person that his or her emotions, thoughts, and behaviors **have causes and are understandable** given the situation or individual's learning history; verifying the facts of a situation.

How To Replace Reassurance?



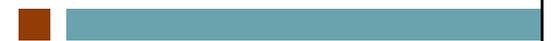
- **Nonjudgmental**; acknowledging someone else's point of view; conveying understanding and empathy without trying to fix things or challenge the person.
 - "I want to make sure I understand. You're feeling anxious and worried because you have a test coming up, is that right?"
 - "I'm not surprised that you want to avoid going to school; every day is a huge challenge for you to make it through with all of the anxiety you've been having about failing or fitting in socially. Most people would want to avoid something so difficult."



Reducing Reassurance



- **What do you think?** Give the child the opportunity to answer the question themselves
- **One worry question/hour.** Limit the number of worry questions per hour/day
- **Delay reassurance.** Insert a predetermined length of time before answering questions to increase tolerance for uncertainty (ask child to rate their fear)
- **Coins in the pocket to use for reassurance.** Use rewards to increase motivation to tolerate anxiety
- **Long-term vs. short-term gain.** With compliancy issues, perform a cost-benefit analysis to increase insight
- **Role model responses.** Practice responding to reassurance questions in session



Take Home Messages



- Family members are critical to pediatric OCD outcomes
- Being parent coaches and aligning with CBT goals are crucial to reduction and remittance of symptoms
- Systematic reduction of family accommodation plays large role in child's success with CBT



Thank you



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