Understanding and Managing the Anxious Behaviors of Children and Adolescents with Autism Spectrum Disorders: Practical Approaches for Schools and Families

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Facing Your Fears: Group Therapy for Managing Anxiety in Children with High-Functioning Autism Spectrum Disorders
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Overview of the Presentation
- Identification of anxiety
- Overview of clinic-based Facing Your Fears Program (Group CBT)
- Teens with intellectual disability
- School based program
- Summary and next steps

Prevalence
- Anxiety symptoms are very common in persons with ASD (Leyfer et al. 2006; Ooi et al. 2011; Simonoff et al. 2008)

Impact
- Anxiety interferes with functioning across environments, with marked financial cost (Kerns & Kendall, 2014; Sze & Wood, 2007; Van Steensel et al. 2013)

Potential to treat
- Anxiety disorders are treatable in general pediatric populations using CBT (Olatunji, Cisler, & Deacon, 2010; Walkup et al. 2008)

Significance
- Anxiety symptoms are very common in persons with ASD (Leyfer et al. 2006; Ooi et al. 2011; Simonoff et al. 2008)

Rates of Anxiety in Youth with ASD
- Population Study (Simonoff et al., 2008)
  - 70% of the sample met diagnostic criteria for Axis I
- Community Samples (Leyfer et al., 2006)
  - 72% of the sample met dx criteria for Axis I
- Clinic Samples (Bruin et al., 2007; Sukholdolsky et al., 2008)
  - 43-80% of the sample met dx criteria for Axis I
- 40% of youth with ASD met criteria for anxiety disorder (van Steensel et al. 2011) compared with 3-8% in TD population (McConachie et al. 2013)

Definitions
- Excessive Persistent Interference
- Anxiety
- Disorder
- Worry
- Fear
- Manassis, 1996
Prevalence of Anxiety in ASD

Common Anxiety Symptoms (Magiati et al. 2017)

“Traditional” anxiety symptoms

Specific fears:
- Animals, bugs, doctors, dark
- Crowds

Separation from caregiver

Social fears:
- Worries what others think
- Teased/bullied
- Unwanted social attention

Chronic worry:
- School performance
- Death and dying
- The future

How anxiety presents

Physiological:
- Arousal; rapid heart rate
- Shaking/restless
- Crying/screaming
- Sleep/eating disturbance

Cognitive:
- Cognitive distortions
- Negative self talk
- Rumination

Behavioral:
- Avoidance/withdrawal
- Reassurance seeking
- Anticipation

Descriptions of Anxious Symptoms

Parents
- Refuses to do things
- Won’t go to school
- Clingy
- “Goes nonverbal”
- “Flies under the radar”
- Gets “stuck in a loop”
- Will get “tough” and say threatening things

School Providers
- Attendance issues and tardies
- Hiding under desks, leaving class
- Perfectionism
- Disruptions in class
- Instigating peer conflict
- Lack of confidence

Distinct Fears in ASD (Kerns & Kendall, 2012)

- Idiosyncratic fears
- Beards, people who look different, mechanical objects
- Transitions/change
- Sensory oversensitivity
- Confusion/fear about social situations (in the absence of negative evaluation)
- Prevention from engaging in special interests

Case Example

- 12 year old male with ASD
- Worries about bees/bugs (won’t go outside at certain times of day), making mistakes, asking for help, talking to new people.

Anxiety In Individuals Who Are Less Verbal (ASD/IDD)

- Irrational and excessive fear, anxiety or worry
- Avoidance accompanied by problem behavior
- Anxious/irrational talk
- Perseveration/repetitive questions
- Increased repetitive behaviors
- Symptoms related to common anxiety situations (e.g., separation, social fears, or specific fears or phobias)
Case Example

- 15 year old male with ASD and Intellectual Disability (ID)
- Fear of dogs, dark, helicopters and wind
- Compulsive need to engage in high fives

When to diagnose? (Kerns, 2017)

- Excessive and overgeneralized symptoms (even considering skill deficits)
- More specific than “emotion regulation” deficits
- Anxiety based interventions could be useful

Complexity of Mental Health Profile In a Clinical Sample of Youth with ASD: Preliminary Findings

Anxiety diagnosis alone (n=0),
Two or more anxiety diagnoses (n=14),
Anxiety plus externalizing diagnoses (n=66),
Anxiety and Mood (e.g., depression) diagnoses (n=10).

(Reaven et al. 2018)

Vulnerabilities to Mental Health Conditions

Development of Anxiety in Youth with Neurodevelopmental Disabilities

Problem Behaviors: non-compliance; aggression; self-injurious behavior

Negative Affect: Anxiety, Depression, Anger, Irritability, Agitation

Emotion Regulation
Real World Impact

- Fear of public bathrooms (e.g., automatic toilets, hand dryers)
- Fear of being late
- Fear of talking to new people/asking for help
- Fear of separating from parents
- Fear of making mistakes
- Fear of hearing the name of certain foods/trying new foods

Impact of Anxiety on Functioning

Anxiety interferes with functioning across home, school and community
- Problem behavior
- Medical complications
- Under-employment
- Financial cost

(Hudson et al., 2001; Kerns & Kendall, 2014; Van Steensel et al. 2013; Velting et. al. 2004; Williams et al. 2014)

Implications for Treatment

Treatment of Choice

Cognitive-Behavioral Strategies for Anxiety: Core Components

- Psychoeducation
- Relaxation
- Social Skill Development
- Problem Solving
- Graded Exposure
- Relapse Prevention

(Clinchburg et al. 2015; Reaven et al. 2012; Walkup et al. 2008; Wood et al. 2013)

CBT for Anxiety in ASD

- Individual treatment (Wood et al. 2009; Storch et al. 2013)
- Group Treatment (Chalfant et al. 2007; Reaven et al. 2012)
- Individual plus group treatments (White et al. 2010; 2013)
- Focus on school aged youth; fewer studies with teens
FYF Treatment Package – Youth with High-Functioning ASD and Anxiety (ages 8-14)

**Total Duration of treatment:** 14 weeks – 1 ½ hour per session

**Modality:** varied; children alone, parents alone, dyads and large group work

**First seven weeks:** Define anxiety symptoms, identify anxiety provoking situations, develop a set of “tools” (somatic management, helpful thoughts, emotion regulation, graded exposure)

**Second seven weeks:** Identify goals and create stimulus hierarchy, apply “tools” across settings, in-vivo graded exposure, video activity to reinforce core concepts

**Booster session:** 4-6 weeks post-treatment

Modifications for ASD

- Basic CBT content is unchanged
- Modifications based on the cognitive, linguistic and social needs of children with ASD
- Integrated social skills curriculum, not a separate module
- Group structure and management
  - Token reinforcement program for in-group behavior
  - Visual structure and predictability of routine
  - Careful pacing of each group session

Modifications for ASD (continued)

- Modifications in teaching basic concepts
  - Prerequisite skills (i.e., feeling vocabulary)
  - Written worksheets
  - Multiple choice lists
  - Drawing and other creative outlets
  - Repetition and practice
  - Video modeling and video self-modeling
  - Strength based
  - Incorporation of special interest

- Parent component critical

Core Components

- Define Anxiety Symptoms
- Increase emotion vocabulary
- Establish common vocabulary
- Identify anxious situations
- Identify physiological symptoms
- Emphasis on symptom intensity and interference

Child Treatment Components

- Establishing a **framework** (March & Mulle, 1998)
  - Provide psychoeducation
  - Externalize anxiety symptoms
  - Compare “anxiety” time vs. “fun” time
  - Create a “team” to manage anxiety
  - Youth strengths emphasized—identity expanded beyond “anxious child”
Child Components (continued)

- Psychoeducation:
  - Worry’s “false alarm” (Chansky, 2004)
  - Establish principle that anxious feelings will pass
  - Emotion regulation
  - “Active” minds (Garland & Clark, 1995)
    vs. “Helpful thoughts”
  - Establish the circular connection between physiological reactions, thoughts, and somatic response

Active Minds

At the zoo one day...

I can’t look at the snakes; they’re so scary.
What if it escapes and comes to my house?
If it’s going to bite me, do I have to get out of the way?
I tried to get out of the cage.
I’m never coming to the zoo again.

What if there are snakes in my backyard?
I can’t play there.

A snake in a cage at the Snake House

Alarm chain reaction!

When Matthew sees a snake in a cage at the zoo...

- First Matthew gets a start.
- Next Matthew begins to get nervous.
- Then Matthew becomes anxious to leave the house.
- Finally Matthew has a heart attack.
What Would You Do?
Common Challenges: Psychoeducation

**Challenges**
- Child denies anxious symptoms, does not think group is appropriate
- Parent-child disagreement
- Child is dysregulated in group; e.g., shut-down/uncooperative
- Child does not understand concepts

**Solutions**
- Go slow, reward small efforts to participate, establish shared vocabulary
- Each person shares opinion, not consensus, takes time to share worries/fears
- Clear expectations with visual support, individualized behavior plan, plan to get to green, individual treatment
- Scaffold; make sure parents understand

Child Components (continued)

- Creating “Steps to Success”
  - List anxiety provoking situations
  - Rank order the situations from 1-8
  - Choose situations that are mild-moderately stressful
  - Practice graded exposure in session
  - Encourage self-reward
- Write an Episode of “Face Your Fears”

Facing Your Fear of Talking on the Telephone

1. Answer the phone from a familiar person
2. Call a familiar person
3. Call a friend from school
4. Call a store to ask for information

Exposure: Steps to Success - Where Do We Begin?

- What I’m working on (target goal)
- How does your fear of XXXX interfere with your life?
- How will you know when you faced your fear of XXXX?
- What are you avoiding because of XXXX?
- What skills do I need to learn in order to be successful facing fears?
  - I will practice facing my fears (how often?)
- Strategies for Success (how to handle worry/fear):
  - Deep breathing
  - Helpful thoughts
  - “Science experiment approach”
- What I’m working for (bigger reward)
  - Use a punch card for regular practice
  - Keep group totals of exposure practice; shared goals

What Would You Do?
Common Challenges: Graded Exposure

**Challenges**
- Child refuses to do exposures
- Parent/child cannot decide which fear or where to begin; Children do not select priority fears to face

**Solutions**
- Select doable first step; use “worry bug”/“helper bug” language; work with another parent/child pair; reward system
- Support child’s selection of fear; emphasize “brave persona”

Facing Your Fears Videos: “Distinct” Fears (Kerns et al. 2017)

- Ugly leaves
- School buses tipping over
- Change
- People who look different
- Handling criticism
- Someone with a different opinion
FYF - Parent Component

- Promote support among participants
- Provide psycho-education about anxiety disorders; learn the basic tenets of CBT
- Establish targets for graded exposure tasks
- Model brave behavior
- Encourage/reward brave behavior in their children
- Discuss parental anxiety and parenting style

Anxiety Components: A Fearful Experience at the Zoo

- Fewer opportunities to practice facing fears
- Decreased Learning + Coping
- Physical Reactions
- Heart racing, sweating, butterflies in stomach as you approach the snake cage
- Behaviors
- Avoid the snake cage and/or zoo
- The snake might get out of its cage!

Modifying FYF for the Full Autism Spectrum

Preschool children

Adolescents

Minimally verbal youth

FYF for teens with ASD/IDD

Modifications for Teens

- Social skill module
- More exposure practice
- Emphasize peer support and group problem-solving
- Less parent/teen direct interaction
- PDA/PayPal touch

Facing Your Fears: Oral Presentations

<table>
<thead>
<tr>
<th>Exposure Steps Completed in Group</th>
<th>Number of People Observing</th>
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<tbody>
<tr>
<td>Deliver a powerpoint to familiar and unfamiliar adults</td>
<td>14</td>
</tr>
<tr>
<td>Deliver a powerpoint to familiar peers and adults</td>
<td>10</td>
</tr>
<tr>
<td>Deliver a powerpoint to familiar peers (e.g., fellow group participants)</td>
<td>5</td>
</tr>
<tr>
<td>Practice delivering power point presentation on a preferred topic out loud at home</td>
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Adolescents with ASD and Intellectual Disability

- Prevalence of psychiatric disorders appears to be higher in ASD/ID groups (53%) compared to rates in people with ID alone (17%; Bakken et al., 2010)

- Case studies have used graded exposure and positive reinforcement (Jennett & Hagopian, 2008; Moskowitz et al., 2017; Riccardi et al., 2006; Runyan et al., 1985)

- Previous research has encouraged the use of cognitive approaches (Vereenooghe & Langdon, 2013)
Is there value in conducting a group treatment for this population?

Parents:
- Support in face of more restricted and isolated developmental period
- Shared strategies and resources
- Unified purpose
- Opportunities to observe others’ successes can be motivating

Teens:
- Can help motivate group attendance
- Increase opportunities for praise of brave identity
- Peer mentoring

Critical First Steps in Facing Your Fears for Teens with ASD/IDD
- Individualized assessment and determination of fit
- Role of problem behavior
- Creating a shared conceptualization of the behavior
- Medical/Psychiatric consultation as needed

Facing Your Fears in Teens With ASD/IDD

What Would You Do?
Common Challenges: Psychoeducation

Challenges
- Behavioral challenges
- Limited awareness of physical state and ability to identify situations that cause anxiety
- Limited ability to generate calming strategies or helpful thoughts

Solutions
- Establish predictability of sessions with behavioral structure, rewards, inclusion of child directed activities
- Have parents identify worries and physical symptoms, have teen sort pictures or descriptors. Repeat and practice!
- Create calming and helpful thought menus. Prompt and practice!

Practice and Repetition of All Psychoeducational Components
- Model and practice deep breathing and use of helpful thoughts with visuals
- Label color/number zones frequently
- Establish consistent routines to practice key coping skills (e.g., deep breathing AND helpful thoughts)
- Reinforce green zone behavior
- Attention to lifestyle issues (exercise, diet)

Core Components of FYF-ASD/IDD

Create exposure hierarchy
- Practice being brave daily by supporting the student to face lower level fears within their hierarchy—make sure to provide visual of “first be brave, then prize”
- Heavily reinforce behavior
- Share and repeat accounts of bravery

Create multiple opportunities to establish and confirm a brave identity and highlight the teen’s ability to use these skills independently
Family Factors

- Family accommodation
- Use of physical affection
- Shift in family relationships
  - Over reliance on one family member, often the mother
  - Reduced sense of competence experienced by other family members

Adolescents with ASD/IDD: Reported Fears

- Dogs/dark/storms
- Separation from parent
- Starting conversations
- Ordering food at a restaurant
- Need to have things even
- Making mistakes
- Need to look in cabinets
- Using the restroom in public places
- Inviting others to get together

Treatment Outcomes

Facing Your Fears in the Clinic

- Case Study (Reaven & Hepburn, 2003)
- Initial group treatment study (N=33) (Reaven et al. 2009)
- Randomized trial with independent evaluator (N=59) (Reaven et al., 2012)
- Adolescent pilot (N=24) (Reaven et al. 2012)
- Follow-up Data (N=35) Hepburn et al. in prep

Bringing Evidence-Based Practice for Youth with ASD and Anxiety to The “Real World”

- Rural Communities (Telehealth) Hepburn et al. 2016
- Specialist Clinic Settings (Reaven et al. 2014, Reaven et al. in press)
- Schools (Drmic, Aljuined, & Reaven, 2017)

Training Clinicians to Deliver FYF:

- Compared three instructional conditions: Manual, Workshop only, Workshop plus consultation
- Examined the effectiveness of instructional method by assessing:
  - Implementation Outcomes
    - CBT knowledge, Acceptability, Fidelity
  - Youth Treatment Outcomes
    - ADIS-P, CGI-S-Severity/Improvement
Methods

- Three group parallel design
- Randomized
- Eight teams of three clinicians

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<th>Condition</th>
<th>Year 1</th>
<th>Year 2</th>
<th>Year 3</th>
</tr>
</thead>
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<td>Manual only</td>
<td>UNC</td>
<td>KKI</td>
<td>Cinn. Children’s</td>
</tr>
<tr>
<td>Workshop only</td>
<td>KKI</td>
<td>Cinn. Children’s</td>
<td>UNC</td>
</tr>
<tr>
<td>Workshop +</td>
<td>UAB</td>
<td>UNC</td>
<td>KKI</td>
</tr>
</tbody>
</table>

UAB = University of Alabama, Birmingham  
KKI = Kennedy Krieger Institute  
UNC = University of North Carolina (TEACCH program)  
Cinn. Children’s = Cincinnati Children’s Hospital

Implementation Outcomes

- Significant improvements in CBT Knowledge following Workshop conditions: $F(1, 18) = 19.8, p < .001, \omega^2 = .48$
- Treatment Fidelity – quality: Significantly greater for Workshop conditions $F(4, 1374)=50.55, p<.0001, \omega^2 = .07$.

Youth Treatment Outcome: Intent to Treat Sample

- Significant decreases in severity for time (CSRs)
  - SEP $F(1, 21.95) = 3.57, p = .072, \omega^2 = .10$. (52% lost)
  - Sp Phobia $F(1, 73-23) = 17.26, p < .0001, \omega^2 = .18$ (42% lost)
  - GAD $F(1, 59.37) = 76.02, p<.0001, \omega^2 = .56$, (39% lost)
  - SOC $F(1, 47.73) = 21.48, p < .0001, \omega^2 = .29$ (29% lost)
- No clear differences between conditions
- 1 Site performed significantly lower than the other 3 Sites
- CGIS-I – Global Improvement: Site 1 – 68%; Site 2 – 43%; Site 3 – 38% and Site 4 – 5%

Working in Schools

- Students with ASD (or other social/communication challenges) present with anxiety/problem behavior in school (Rotheram-Fuller & MacMullen, 2011).
- Efficacious interventions frequently unavailable in school settings
- Schools are the location of choice (Mychailyszyn et al., 2011; Van Asch & Mayer, 2009).

Source of Intervention Adaptation

- FYF – School Based (Singapore) Reaven (Drmic, Aljunied, & Reaven, 2017)
- Vocabulary, video-modeling activity, parent involvement
- Core CBT concepts stayed the same; eliminated optional activities
Key Concepts and Activities in FYF-SB

Session 1: Welcome & Introduction
- Getting to know you
- Learning about emotions
- Everybody worries sometimes
- Self-reflection: How I react/feel when I worry

Session 2: Understanding Worry
- Time Spent Worrying
- Externalizing worries: Worry bugs
- Real dangers vs. False Alarms; Physiology
- Calming & Relaxing Activities, Deep Breathing

Session 3-4: Understanding and Identifying Worries
- Stress-o-meters: measuring anxiety
- Active Mindful Thoughts
- ‘Plan to get to green’
- Identifying priority worries

Sessions 5-10: Practice Facing Fears
- Facing Fears
- Creating exposure to success
- Review & Graduation

Three Parent Sessions:
Session 1: Overview of FYF-SB
Session 2: Introduce tools/strategies
Session 3: Wrap-up and relapse prevention

FYF: Lighting a Bunsen Burner in Science lab
1. Observe teacher switching the Bunsen burner off and on
2. Pretend to turn on the gas and "light" the burner with a prop
3. Turn on the gas and "light" the burner with a prop
4. Teacher turns on the gas, lights the burner with a real lighter
5. Pretend to turn on the gas, light the burner with real lighter
6. Turn on the gas by myself, light the Bunsen burner with a real lighter

Facing Your Fears in Singapore
(Dr. McAneney & Reaven, 2017)

Implementation Outcomes
- Training workshop: 1-6 (M=5.05)
- CBT knowledge: t(29)=2.82, p=.009
- Parent acceptability of FYF-SB; Useful (M=4.33; Enjoyable M=4.1)

Treatment Outcomes (N=44)
- 22 Secondary Schools; 42 specialists trained
- 86% treatment completion
- Significant reductions in parent report of youth anxiety, SCARED, p=.011
- Significant reductions in youth self-report of anxiety, SCARED, p=.001

FYF in Denver, Colorado
- Low income Racially/ethnically diverse communities
- Denver Public Schools
- Littleton Public Schools
- Cherry Creek School District

Source of Intervention Adaptation
(Chambers & Norton, 2016)

Interdisciplinary school teams with consultation from mental health; integrated school settings
- Elementary/middle school students with social/communication challenges and/or ASD
- Uninvolved informed by key stakeholders
- Low income/underrepresented racial/ethnic minority students
- Core CBT concepts stay the same; emphasize emotion regulation/anxiety

Sources of Intervention Adaptation: FYF: School Based (Colorado Public Schools) Reaven, HRSA #R41HC310750-00
Summary/Future Directions

- Anxiety can be treatable for youth with ASD, even for individuals with ASD/ID.
- Some advantage to attending a Workshop for FYF, but reductions in anxiety for Manual condition.
- Non-mental health teams can deliver FYF.
- Managing anxiety is empowering!

Next steps:
- Continue to implement FYF in the community, but improve outcomes.
- School-based programs in Colorado.
- More work with ASD/ID.
- Young adults.

Real World Success

- Using public bathrooms at airports, school, etc.
- Walking into the classroom, even when late.
- Talking to new people; asking for help at a store.
- Going to another part of the house; outside; left alone.
- Turning in homework, making mistakes on tests.
- Hear the name of foods, decreased bullying.

Treatment for anxiety includes:

- Paying attention to your mind.
- Paying attention to your body.
- Facing fears!

To summarize...

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Thank You Very Much!

YOU MUST DO THE THING YOU THINK YOU CANNOT DO.

– Eleanor Roosevelt

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