Managing the Anxious Behaviors of Children and Adolescents with Autism Spectrum Disorders

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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

- Overview of clinic-based Facing Your Fears Program (Group CBT)
- Modifying FYF (teens with ASD, school settings)
- Data update
- Modifying FYF for Teens with ASD and Intellectual Disability
- Future Directions
- Questions?
Impact of Anxiety on Functioning

- Anxiety interferes with functioning across home, school and community
- Under-employed, risk for substance abuse, and development of other psychiatric disorders
- Higher risk for challenging behaviors
- Higher risk for developing medical conditions such as GI and sleep disturbance
- Without intervention, symptoms may persist into adulthood
- Evidence of increased financial cost for individuals with both ASD/Anxiety

(Hudson et al., 2001; Kerns & Kendall, 2014; Van Steensel et al. 2013; Velting et al. 2004; Williams et al. 2014)
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
Development of Facing Your Fears: Contribution of JFK Partners/LEND

- Clinical work
- Trainees – interdisciplinary from the beginning
- Develop/implement/debrief/revise/
- Over 25 trainees – for research/treatment development
- Over 25 trainees post-manual development
UC-SOM Colleagues/Trainees and Research/Clinical Teams

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- Eileen Leuthe, Ph.D.
- Eric Moody, Ph.D.
- Lindsay Washington, Ph.D.
- Laura Santerre-Lemon
- Caitlin Walsh, Ph.D.
Cognitive-Behavioral Therapies
*Treatment of choice for anxiety disorders*
(Olatunji et al. 2010; Silverman et al. 2008; Walkup et al. 2008)

*AND*

*for treatment of anxiety disorders in youth with ASD*
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
Cognitive-Behavioral Strategies for Anxiety: Core Components

- Psychoeducation
- Somatic Management
- Cognitive Restructuring
- Problem Solving
- Graded Exposure
- Relapse Prevention

(Ref: Velting, Setzer & Albano, 2004).
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”
Michael worries about a lot of different things. He spends a lot of his time during the day worrying!

Michael has no time to do anything fun. He spends almost all of his time worrying!
Annie sometimes gets nervous about tests, and is a little scared of big storms. How much time do you think she spends worrying?

Time Annie spends worrying

- A little
- Some
- A lot!!
How much time do YOU spend worrying NOW?

Write down your worries here!

Draw a line to show how much time you spend worrying

A little
Some
ME!!
A lot!!
MY "WORRY BUG"
Its' name is: Stupid Spider
MY “Helper BUG”
Its' name is: **Super Kid**
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
Measuring Anxiety

THE ZONES OF REGULATION
A CURRICULUM DESIGNED TO FOSTER SELF-REGULATION AND EMOTIONAL CONTROL

Written and Created by
Leah M. Kuypers

A “5” Could Make Me Lose Control!
NEW! Picture word cards for younger children and those with more severe communication needs

Activity-based for evaluating and supporting highly intense students

Kunn Buron
Alarm chain reaction!
when Matthew sees a snake in a cage at the zoo...

1. Physical Feeling
   First Matthew starts to get butterflies in his stomach....

2. Thoughts
   Oh no, it's a snake. I don't like snakes!
   Then, his heart starts beating faster, he gets grouchy, his head starts to hurt, and the butterflies in his stomach get worse....

3. Physical Feeling
   What if it gets out? It might bite me.
   Finally, Matthew becomes so anxious he leaves the room. His head really hurts and he's really upset.

   Thoughts
   It's coming after me! I have to get out of here! I'm never coming to the zoo again!
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 Fears of Dogs

1. Look at pictures of dog in a book or on the Internet
2. Watch videos of dogs
3. Walk past a dog on a leash, maintaining a distance of 10 ft.
4. Walk past a dog on a leash, maintaining a distance of 5 ft.
5. Stand next to a dog
6. Stand next to a dog and pet it.
Exposure: Where To 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”
  - Fear reduction vs tolerance of fear (Abramowitz et al. 2013)
- What I’m working for (bigger reward)
  - Use a punch card for regular practice
  - Keep group totals of exposure practice; shared goals
Facing Your Fears Videos: Common Fears

- Making mistakes
- Dying
- Staying home alone
- Elevators
- Doctors
- Dentists
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
Modifications for Teens

- social skills module
- More exposure practice
- Emphasize peer support and group problem-solving
- Less parent/teen direct interaction
- PDA/iPod touch
iPod Touch Screens:

Context: Facing Fears

How anxious when starting?

- Anxious at beginning
  - (0) Not at all
  - (1)
  - (2) A little bit
  - (3)
  - (4) Some
  - (5)
  - (6) A lot
  - (7)
  - (8) Very very

Use any of these to help?

- Helpful thoughts
- Calm/relax activity
- Think other things
- Fight back w/ fact
- Wait worry go away
- Do another activity
- Talk to Mom/Dad
- Other
Treatment Outcomes
Data Update: Facing Your Fears in the Clinic

- **Case Study** (Reaven & Hepburn, 2003)
- **Initial group treatment study** (Reaven et al. 2009)
  - N=33; significant reductions in anxiety
- **Randomized trial with independent evaluator** (Reaven et al., 2012)
  - N=50; Psychiatrically complex; Post-TX - Fewer # of Dx (including loss of GAD); 50% improvement compared to 8.7% TAU – (effect size 1.03);
- **Adolescent pilot** (Reaven et al. 2012)
  - N=24; significant reductions in anxiety and challenging behavior; 46% of teen participants “much improved” or “very much improved"
Data update (continued)

- **Follow-up:** (N=47 completed FYF; 35 parents completed 1 year follow-up) (Hepburn et al. in prep)
  - SCARED: pre-treatment (M=31.93, SD=11.85); post-treatment (M=27.36, SD=12.11); one year follow-up (M=19.06, SD=10.34)
  - Significant improvement at 1 year follow up relative to post-treatment scores \( t(1,34)=4.64, p=.0001 \)
Challenges: Research to Practice Gap

Green (2008)
Bringing Evidence-Based Practice for Youth with ASD and Anxiety to The “Real World”

- Specialist Clinic Settings
  - IWK Centre; UAB; KKI; UNC; and Cinn Children’s
  - (Reaven et al. 2014; Reaven et al. in prep)

- Reaching rural communities (Hepburn et al. 2016)

- Schools (Drmic et al. 2017)

- Mental Health Centers
Anxiety/behavior challenges common in schools

Efficacious interventions unavailable in schools

Disparities in access to mental health services

Schools are the location of choice

(Mychailytsyn et al. 2011; Rotheram-Fuller & MacMullen, 2011; Van Acker & Mayer, 2009)
Facing Your Fears: School-Based Version (FYF-SB) in Singapore
Adaptations Traffic Light Guide:

**Green Light Adaptations**
- Vocabulary changes to be more age/culturally appropriate
- Age appropriate fears used as examples
- School setting instead of clinic setting

**Yellow Light Adaptations**
- Video substitution for graded exposure example
- Optional activities eliminated due to age
- Change in format of parent participation

**Red Light Adaptations**
- Decrease in treatment dosage (intentional)
- ‘Adherence to Tx’ data not collected (unintentional)

Centers for Disease Control and Prevention, Division of Reproductive Health, & ETR Associates
Who Can Deliver FYF in Schools?

- Special educators
- Speech/language pathologists
- School Psychologists/counselors
- Occupational/physical therapists
- BCBAs

- Mental health professional as team member/consultant
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

**Sessions 3-4**
Understanding and Identifying Worries
- Stress-o-meters: measuring anxiety
- Active Minds & Helpful Thoughts
- ‘Plan to get to green’
- Identifying priority worries

**Sessions 5-10**
Practice Facing Fears
- Facing Fears
- Creating exposure hierarchies/steps 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
Results - School program (Drmic, Aljunied, & Reaven, 2017)

- **Implementation outcomes**
  - CBT Knowledge improved
  - Positive reviews of training workshop
  - Positive acceptability - facilitators/coaches/parents

- **Preliminary effectiveness**
  - 22 Secondary Schools; 42 specialists/psychologists trained
  - Significant reductions in anxiety according to both child/parent report (n=44)

- **Limitations**
  - No treatment fidelity measured
  - No active control group; lack of randomized design
  - Small sample size
Challenges in Conducting Group CBT

- Behavior
- Behavior
- Behavior
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)

- The assessment of anxiety in teens who have reduced verbal abilities, however, can be challenging.
Guidelines for Assessment of Anxiety Symptoms In Individuals with IDD

• Assess cognitive, overt behavioral, and somatic responding across contexts
• Use multiple measures including interview, questionnaire and behavioral observations
  • Anxiety, Depression and Mood Scale (ADAMS, Esbensen et al. 2003)
• Speak to multiple providers (e.g., parents, teachers)

(Hagopian & Jennett, 2008)
What might anxiety look like in individuals with fewer verbal skills (ASD/IDD)?

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

(Hagopian, Lilly, & Davis, 2017)
Additional Indicators of Anxiety: What are they avoiding?

Simple avoidance

Avoidance of non-preferred items + Non-fearful response = Anxiety

Anxious avoidance

Avoidant behavior + Fearful Response = Anxiety

Hagopian & Jennett, 2014
Anxiety Treatment Research

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

- Cognitive approaches in this population is now encouraged (Vereenooogh & Langdon, 2013)
Adapting Facing Your Fears for Teens with ASD/IDD

• Group format
• 14 sessions
• 3 parent only sessions, hour and a half in duration;
• 11 parent/teen sessions, 50 minutes
Facing Your Fears in Teens With Intellectual Disability

1. Begin with Parent Only Sessions
2. Functional Assessment of Anxiety and Problem Behavior
3. Emphasis on Emotion Regulation
4. Parent Teen Dyads and Parent Involvement in ALL Sessions
5. More Naturalistic Exposure
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
Behavioral Supports to Facilitate Group Participation

Within the Session:

- Establish predictability via visual structure
- Careful pacing: Alternate between child- and adult-directed activities as a means of building rapport and managing behavior
- Create clear reward system
- Reduced session time

Across the Group:

- Attempt to match participants on language level
- Have handouts that vary based on language level
Building Foundation Skills for Treatment

• Model and practice deep breathing
• Establish consistent routines surrounding practice of key coping skills (e.g., deep breathing, emotion identification)
• Attention to lifestyle issues (exercise, diet)
• Reinforcement of green zone behavior
Value of Cognitive Component

Irrespective of language level, many youth can benefit from helpful thoughts (i.e., cognitive inserts)

Pay attention to negative self talk and actively replace with helpful thoughts

Focus on replacement not identification and challenge of negative cognitions
• 15 year old teen
• ASD and Intellectual Disability
• Phrase speech; literacy at approximately 2\textsuperscript{nd} grade
• Anxiety:
  • Fear of dogs
  • Compulsive need to do high-fives
  • Need to have mom by his side at bed time
What happens to my body?

1. Calm, happy
2. "Uh-oh," nervous
3. Scared, freak out
4. Cover ears, stay close to mom
5. Listen to music, crying
6. Walk around, play computer games
7. Freeze, throw chairs
8. Run to basement, repeat things
Situation
Where am I on my stress-o-meter?

Calm My Body

Calm My Mind

8
7
6
5
4
3
2
1

I can do it!
Talk to a new person
See a dog

Deep breathing
Take space
Take a walk
Exposure

• Facing fears a little at a time is done in a similar fashion to how we conduct exposure in our traditional Facing Your Fears program
• Parents play a critical role in determining the fear to face—we base this on degree of interference
• Youth “buy in” for exposure can be a challenge; however, visual schedules and rewards have been instrumental in supporting engagement
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
Challenges

- Recruitment
- Matching youth within groups
- Determining whether behavior was anxiety based and should be a target of treatment
- Supporting families in implementing approaches outside of clinic
- Length of treatment: balancing “dosage” with parents’ demanding schedules; could not alternate between parent only and child sessions like originally planned
- Tracking change over time (i.e., assessment instruments)
Lessons Learned

• Some teens appeared to have significant reductions in anxiety, whereas others have not (as measured by the ADAMS, SCARED, and FSSC-R)
• Decreases observed in lethargy subscale of Aberrant Behavior Checklist
• Parents have reported increased sense of competence in managing anxiety symptoms and sharing the parenting role
• Parents report enjoying the group nature of treatment and report high satisfaction with treatment components
Important Next Steps:

• Implementation in “real-world” settings; schools and mental health centers
• Continue to extend treatment programs to individuals with ASD/ID
• Develop evidence-based treatment programs for adults with ASD
• Examine mechanisms of change
• Preventing anxiety/building resilience
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
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