

Anxiety in Adults with Williams Syndrome

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GENERAL DEFINITION OF ANXIETY

What is Anxiety?

• Some level of anxiety is “adaptive” (necessary and helpful) prepares the individual to avoid threat

• Anxiety as a personality trait – “negative affectivity” – everyone has some tendency toward anxiety, but we vary in how much

"Anxious" person

Thoughts incorporate themes of danger and vulnerability

Feel incapable of preventing or managing these risks

 Threats may be physical, social, or psychological
Three Part Model of Anxiety

- Avoidance
  - Trembling voice, lip
  - Crying
  - Nail biting
  - Picking at nails
  - Physical proximity
  - Verbalizations
  - Hands over ears
  - Questions about the future

- Behavior
  - Thoughts of being scared
  - Expecting bad things
  - Thoughts of danger
  - Thoughts of inadequacy
  - Thoughts of appearing foolish
  - Difficulty concentrating
  - Feeling unable to cope

- Physiology
  - Heart racing
  - Sweating
  - Muscle tension
  - Palpitation
  - Breathing
  - Nausea
  - Headache
  - Stomach upset
  - Dizziness

- Thoughts
  - Kinds of thoughts vary with age, developmental level, and life experiences

Even in unambiguous situations

Anxiety in Williams Syndrome

- Who will take care of me when my parents can’t?
- Why can’t the doctor figure out what’s wrong with me?
- When are we going to...?
- What is coming next?

Depressed Mood

- Major Depression diagnosis: Mood lasts at least 2 weeks and a change from usual mood
- Dysthymia: may not have the same level of anhedonia or feelings of worthlessness, but lasts the majority of days for 2 years or more

- Thoughts/Feelings
  - Sadness
  - Irritability
  - Feelings of worthlessness
  - Thoughts of death

- Lack of interest in activities that were previously enjoyable
  - Changes in:
    - Appetite/weight
    - Sleep
    - Concentration
    - Activity level

- Depressed Mood
Overlap Between Depression and Anxiety

Having anxiety often places someone at increased risk for the development of depression.

Behavioral Responses

- Avoidance
- Gratuitous arm, hand, and leg movements
- Trembling voice
- Crying
- Feet shuffling
- Screaming
- Nail biting
- Skin picking
- Thumb sucking
- Rigid posture
- Eyes shut
- Avoidance of eye contact
- Clenched jaw
- Stuttering
- Physical proximity
- White knuckles
- Trembling lip
- Certain verbalizations
- Immobility
- Swallowing
- Hands over ears
- Walking rituals

Physiological Responses

- Heart rate
- Basal skin response
- Palmar sweat index
- Galvanic skin response
- Muscle tension
- Skin temperature
- Respiration
- Palpitation
- Breathlessness
- Nausea
- Pulse volume
- Headache
- Stomach upset
- Stomachache
- Urination
- Defecation
- Vomiting
- Labored breathing
- Blurred vision
- Numbness
- Dizziness
- Flashes/chills

Some people are more aware of these bodily sensations than are others.
Thoughts

- Thoughts of being scared
- Thoughts of monsters
- Thoughts of being hurt
- Images of monsters
- Sense of impending doom
- Images of wild animals
- Thoughts of danger
- Self-deprecatory thoughts
- Self-critical thoughts
- Thoughts of inadequacy
- Thoughts of incompetence
- Images of bodily injury
- Thoughts racing
- Thoughts of imminent death
- Thoughts of appearing foolish
- Blanking out
- Thoughts of going crazy
- Difficulty concentrating
- Forgetfulness
- Thoughts of contamination
- Images of harm to loved ones
- Repeated thoughts or questions about the future

Kinds of thoughts vary with age, developmental level, and life experiences

COURSE OF ANXIETY IN ADULTS WITH WILLIAMS SYNDROME

Anxiety in WS

- Most common published anxiety diagnoses in WS:
  - Generalized Anxiety Disorder (GAD)
  - Specific Phobias
  - Panic attacks
- Typical manifestations:
  - Perseveration
  - Anticipatory Anxiety

<table>
<thead>
<tr>
<th>Ages</th>
<th>8-10</th>
<th>11-16</th>
<th>Adult (estimate)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any Anxiety Disorder (GAD, separation anxiety, panic disorder) + ADHD</td>
<td>65%</td>
<td>40%</td>
<td>75%</td>
</tr>
<tr>
<td>Specific Phobia</td>
<td>45%</td>
<td>60%</td>
<td>55%</td>
</tr>
<tr>
<td>OCD</td>
<td>0%</td>
<td>5%</td>
<td>3%</td>
</tr>
<tr>
<td>Depression</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

Adapted from Leyfer et al 2006.
Manifestations of Anxiety in WS

**Childhood**
- Specific Phobias (certain sounds, storms, doctors office/blood drawing)
- Perseveration (getting stuck on something, worry about upcoming events)
- Medical/behavioral concerns (emitting, scratching)

**Teens/Early Adulthood**
- Most of the above, plus...
- Emotional lability or acting out/ "teenage" behaviors
- Nail biting/picking/flushing
- Inappropriate behaviors
- Obsessions
- Physical manifestations (somatization)

**Mid-Late Adulthood**
- Most of the above, plus...
- Increased focus on medical issues
- Worry about a family member’s health and their own health
- Decreased independence/level of functioning

Less Common manifestations

- Certain behaviors are rare, but not unheard of:
  - Frequent calls to 911
  - Sexual Fetishes/Behaviors
  - Ritualistic and/or increased rigidity of behaviors
  - Hoarding
  - Binge eating
  - Altering medication routines

- You are not alone if your WS family member is experiencing these!

General Course of Anxiety

- General level of anxiety “waxes” and “wanes” overtime
- Explanations may be evident or not
- Occasionally, anxiety may escalate to a “crisis”
Anxiety Crises

• Significant escalation in anxiety is uncommon, <10% in our estimation
• May be marked by a decline/change in an individual’s baseline level of functioning or behavior
• Parents tell us:
  – “I just want my happy child back”
  – “My child is talking about harming him/herself”

Anxiety Crises (continued)

• In our experience, there are often triggers for the crisis.
• However, trigger may not be readily apparent to family and caregivers
  – May be a significant event
  – May be a seemingly insignificant event
• Bear in mind, individuals do get better with a combination of supportive interventions and time!

Common Triggers

- Death of a Family Member
- Death of a Pet
- Difficulty with a given task
- Sexual Abuse
- Someone said something at work/school
- A medical problem
- Overhearing a medical discussion
- A news story or tv show
- Changes at school/work/day program
- A Breakup
- Hearing about a friend’s medical experience
Medication to Treat Anxiety

• In our practices, we DO NOT PRESCRIBE MEDICATIONS FOR MENTAL HEALTH ISSUES
• Your PCP may feel comfortable prescribing certain meds
• Even so, for longer term use of medication, consulting with a psychiatrist is preferred
  — Ideally someone experienced treating adults with special needs

Major classes of Anti-anxiety medications

1. Benzodiazepines: Short and long acting
   Valium-like medications
2. Azapirones: Example: Buspar
3. SSRIs*: Newer generations of
   Prozac-like medications
4. Beta-blockers: Example: Propranolol

* Selective serotonin reuptake inhibitors
Support Strategies

Helping Adults with Williams Syndrome to Manage Anxiety

Counseling

- The challenge: finding a clinician who is familiar with WS or is open to learning about the WS profile.
- The importance of the therapeutic approach and experience: clinicians who have worked with ASD or other cognitive disabilities.
- Clinicians trained in Cognitive-Behavioral Theory (CBT).
- Clinicians who work with children and/or adolescents are often preferable for this population.
- Clinicians need to be engaged with the system that supports the WS adult—often parents and caregivers, in order to get the most accurate picture of the level of functioning and progress (or lack of) over time.
- Occupational Therapists and anxiety management—alternative to typical clinicians (social workers, mental health counselors).
What should the goals of therapy be?

- SKILL BUILDING in the areas of:
  - Body awareness (the mind-body connection).
  - Self-regulation.
  - Connecting thoughts and feelings.
  - Thought stopping and replacing.
  - The overall goal should be to develop a “tool box” of techniques and skills that the individual can utilize in real life.
  - It is vital to learn the skills when calm and to practice them in the therapeutic environment and at home so that they can then be accessed in moments of anxiety.
  - There is no “one size fits all” approach - therapy should be tailored to the individual and the therapist should be willing to modify the approach as needed.

- Utilizing strictly “talk” therapy does often NOT have ongoing benefits for WS adults.
  - It can be helpful to allow the individual the time & space to “vent”.
  - It can allow for a temporary reprieve of anxious feelings.
  - It does not teach the skills of how to manage anxiety outside of the therapy office.
  - It can exacerbate the WS adult’s tendency to perseverate on anxious thoughts.
  - The people-pleasing aspect of the WS personality can interfere with this treatment modality.
  - The WS adult’s ability to remember and implement what is discussed is often limited.
  - Remember that the emphasis should be education and skill-building!

What are some of the skills that can be helpful for WS adults to learn, both in the therapy office and at home?

- Identifying what anxiety looks and feels like.
- Identifying what triggers for anxiety are. Individuals need to be aware of what their triggers are and/or how their body feels when anxious before they can learn to implement any regulating strategy.
- Learning self-calming strategies (visualization, deep breathing, progressive relaxation).
- Learning how to manage anxious thoughts (thought journal/jar, daily check-in sheet, written problem-solving plan, positive thought/mantra tool).
- Utilizing special interests as quick & dirty calming strategies (photo book, calming item, humor, music, videos).
- Modifications to environment, or, the importance of distraction (exercise, hobbies, social groups, work, increase of supports to be & feel successful).
Identifying what anxiety looks & feels like

- Work to identify a situation that typically leads to anxiety, or worry thoughts. Clinician may enlist the help of family/caregivers to develop a list.
- When this happens, where do you feel anxiety in your body? Utilize a visual drawing of the body.
- What happens to my body when I am worrying?
- What do I do NOW when my body is feeling this way that is helpful? You do not want to change something that may already be working for an individual.

Identifying triggers for anxiety: use Behavior Log to track data.

<table>
<thead>
<tr>
<th>Day</th>
<th>Time</th>
<th>Situation</th>
<th>What am I feeling?</th>
<th>What did I do?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monday</td>
<td>6:30 am</td>
<td>Johnny was getting ready for work and was picking at skin around nails.</td>
<td>Nervous</td>
<td>Koosh ball given.</td>
</tr>
<tr>
<td>Monday</td>
<td>4:30 pm</td>
<td>Getting ready for dinner, Johnny refused to help with prep.</td>
<td>Unable to report a feeling, but stated he &quot;wasn't sure&quot; if he knew how to make the meal.</td>
<td>I started dinner and had Johnny handle some of the easier tasks.</td>
</tr>
<tr>
<td>Wednesday</td>
<td>6:30 am</td>
<td>Again picking at nail skin when getting ready for work</td>
<td>Reports he is excited to go to work.</td>
<td>Asked if there was anything that was causing him upset at work and he was told it was a ball gone again.</td>
</tr>
</tbody>
</table>

- Identifying triggers for anxiety: use Feelings Chart to track different situations. This will help them to start linking situations, feelings, and behavior. Tools can then be implemented to be proactive regarding situations that typically cause anxiety.

  -- Positive Event | My Feelings
  I received a phone call from my brother. He told me he's coming to visit in April! | Happy and excited. |
  I finished all my work today. | Relieved. |

  -- Negative Event | My Feelings
  A coworker spoke to me in a loud voice. | Scared and nervous. |
  My mom scheduled my dentist appointment. | Worried and frightened. |
Self-Calming Strategy: Visualization

- Individuals can utilize visualization strategies to support the mind-body connection in managing anxiety. Visualization is simply picturing an image or recalling a particular sensation that brings about positive feelings.
- Some WS adults are particularly skilled at this, and can “call up” or visualize soothing images with simple prompting to do so and a relaxing space to do this in, or they can use this quickly in moments of anxiety to refocus and reset. Examples: a favorite pet, the feel of sunshine, a vacation spot, a treasured memory.
- Others benefit from guided imagery, or using a script to help them get to a relaxed state and call up images in their brain. Scripts can easily be found via a google search!
- Taking 10 minutes per day to use this strategy can be effective in promoting a more relaxed state. Once it becomes rote, it can also be used before a situation that has previously been anxiety provoking.

Self-Calming Strategy: Deep Breathing

- Diaphragmatic (or belly) breathing is an extremely simple yet effective way to calm the body and brain. It involves breathing slowly and deeply from your chest while focusing your attention on your belly as it rises and falls.
- It is key to be watching and focusing on the belly as it distracts the brain from anxious thoughts and allows for centering.
- The easiest way to learn this is to use an item that can be placed on the belly, lay down, and focus on getting the item to go up and down using deep breaths.
- It is important to practice this each day in order for it to be effective!

Self-Calming Strategy: Progressive Relaxation

- This is a strategy that is not used in the moment of anxiety as a quick fix. Rather, regular use of relaxation promotes an overall better state of well-being in the individual. WS adults may do this each morning, to have a calm body/mind before tackling their day, or they may do this at night, to allow for a release at the end of the day.
- Using a “whole body relaxation” script/CD/app, the individual is prompted through steps that aid in reducing stress.
- This is best taught initially by a practitioner familiar with this technique. The practitioner can then assign “homework” for the individual to do at home that reinforces learning.
Managing Anxious Thoughts

Daily Check-in Sheet: This would need to be done with support! Should take no longer than 15 minutes each day, and allows for a release of anxiety.

Did I have any worry thoughts today? What were they?
I was worried about my friend John. He didn’t say hello to me when he came to work.

I was worried that I won’t get to go out this weekend. I don’t have a ride to group.

Will these thoughts help me? Why?
No, I kept thinking about them.

No. But I always worry if I’ll have a ride!

What can I think that is different that will help me to not worry?
John was probably just busy. He says hi to me most days, but not every day. We’re still friends.

I’ve been able to go to group almost every weekend. My caregiver always lets me know on Friday if I’ll have a ride.

Did I have any happy thoughts today? What were they?
I was happy to go hang out with my aunt after work. We laughed! She helped me make dinner.

I was happy that I’m getting paid tomorrow!

Managing Anxious Thoughts

Building Problem-Solving Skills:

I am feeling worried! Doing this worksheet can help me to figure out a plan for how I can feel better.

Why am I worried? How do I define the problem?
I’m worried because I have to go to the dentist next week.

I’m worried about my friends. I saw them fighting this morning.

Is it a big problem or a little problem?
For me, it is a big problem. I always worry about the dentist.

It is a little problem. Friends sometimes fight. It’s not as big to me as the dentist.

What are two things I could do to feel better about the problem?
I can try not to think about the dentist by keeping busy and watching my favorite TV show. I can think about the last time I went to the dentist and remind myself that the appointment went really well.

I can talk to my mom and tell her what happened. I trust her to give me good advice. I can remind myself that their fight doesn’t involve me.

Managing Anxious Thoughts

Positive replacement thought/mantra tool: WS individuals can get stuck in a feedback loop of the same anxious thoughts. A helpful tool can be to learn to STOP the anxious thoughts by replacing them with positive thoughts/mantras that they have chosen ahead of time. These aren’t solutions to the anxious thoughts, rather they are simply peaceful thoughts that are calming. Carrying around a card with the thoughts on it, or keeping the thoughts in the Notes section of a smartphone, can be easy ways to make sure the thoughts are easily available for reference.

“I am being silly with friends.” “I am listening to my favorite song.” “I am petting my cat.” “I love to smile and make people happy.” “I am at the beach.”
The Use of Special Interests

- Humor! Huge for WS individuals.
- Videos- of animals, funny scenes, favorite clips, etc.
- Music: Key in the lives of most WS individuals and extremely effective in managing anxiety, both as a daily tool and in the moment.
- Calming item- many WS adults can carry, either in their pocket or on a lanyard, a special item that reminds them that they can persist through an anxious moment.
- Use of favorite characters: “What would Superman do?” therapist can work in session to create a story of how this person handles anxiety and succeeds.
- Photo book- A small, pocket size book that contains photos of favorite people, places, animals, etc. and can be flipped through quickly.

Structure, or the Importance of Distraction

- The single best way to manage anxiety in WS adults is to promote a life that has as much structure and manageable activity in it as possible. We cannot perseverate on our anxious thoughts when our brain is busy with other things!
- WS adults will perseverate and “stew” on anxious thoughts when faced with large amounts of down time.
- Having a schedule for each day, and incorporating down time and what to do during it, can be tremendously helpful.
- Incorporating exercise, social/hobby groups, work/volunteering is essential.

Final Thoughts

- This is a lifelong process. The management of anxiety in WS adults (and in many typical adults!) is not a “one and done” in terms of treatment.
- Learning new skills takes time, and there will be periods of regression and re-learning. Patience is key.
- WS adults will need help to make these strategies work-they should not be expected to manage any of this independently. It has been my experience that WS adults continue to need in-person support throughout their lifetime.
- With the support of caregivers and professionals, WS adults can continue to work through the anxiety and lead meaningful lives.
Session Leaders

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