Treating Fears and Phobias in People with Williams Syndrome: An Introduction

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Disclosure
I will be presenting our original work today, some of which is included in the book we co-authored (Levine and Chedd):

Anxiety/phobias are common in people with WS (Really!?!)

Especially common phobias include:
- Medical procedure related
  - Shots, Doctor visits, Dentist etc
- Sound related
  - Vacuums; alarms; whistles; sirens; scoreboard buzzer; flashing; balloons popping; thunderstorms; fireworks; movie theatre
- Other Sensory related
  - Haircuts, band-aids, sunscreen, bugs; foods; escalators, elevators, flying, crowds, kinds of clothing, escalators, hearing aid
- Sensory + Intense Emotion
  - Happy Birthday Singing; Babies crying; Coughing;
  - Crowd eruptions: applause/laughing
- Negative emotion in others especially anger even mild anger

Anxiety is the most common presenting problem for all children in psychotherapy

“Useful” adaptive fear / anxiety vs interfering maladaptive phobia

- Some fear is very adaptive to help us avoid danger
- ‘fearless’ people are at huge risks
  - e.g. Challenges of lack of social anxiety

12-20% of children seen in MH settings present with extreme anxiety (Knell & Dasari, 2006; Schawfer, 2009)
- Includes GAD, OCD, phobias
Fear becomes maladaptive when:

- It is way out of proportion with the trigger event
- It causes intense distress in the person (e.g., upset every day before school/work in case there might be a fire drill or thunder etc)
- It causes person to avoid situations that would otherwise be fun and productive (e.g., birthday parties; flying places)

Anxiety is especially common in people with many different developmental disabilities:
- Autism
- Williams syndrome
- Fragile X

How does a phobia develop and evolve?

- Typically there was some event or event chain that was highly distressing
- Then the person dreads this happening again
- The fear ripples to things associated with it happening (e.g., going to school, clouds in the sky that could mean thunderstorms etc)
- The fear ripples to ANTICIPATING the event 'anticipatory anxiety' can be especially debilitating
- Then ripples to anticipating anticipating — fear of fear... of fear

So in the face of this cycle what does a person naturally do?

- Avoid the feared situation whenever possible (so one doesn't get practice in experiencing it as not so bad)
- Anticipate it with great anxiety so then one's experience of it is colored by high levels of emotional distress
- Parents/teachers may help child avoid feared experience not wanting to cause unneeded distress
- One never gets to experience just the event without the anxiety to
  - Re-learn a new emotional response
  - Relearn one's thoughts or cognitions about the event

Ideally one could magically...

- ...experience the feared event without fear a few times and this would fix the problem
- One would no longer THINK it would be so horrible — so no more anticipatory anxiety. One would also learn one CAN be fine with it so would no longer underestimatone one's capacity to be OK. Then one could go back to 'normal' and not have all the associated fear
+ Sometimes this happens ‘accidentally’ and cures the phobia

- Helium Balloon vanishing phobia – I accidentally let it go and my patient was so surprised as it had been tied down, he didn’t have time to have anticipatory anxiety – no fear – over and done with!
- Needle phobia in friend until she gave birth – ‘implosion therapy’ of needles – and they were the least of her concerns – so she experienced needles without fear of them – fear is gone
- But one doesn’t want to leave it to chance as often these ‘opportunities’ don’t come up and sometimes when they do they are frightening anyway and perpetuate the phobia

+ So with treatment...

- ... The actual event may still be unpleasant or horrible or not too bad, but what one can very often treat quite effectively is the anticipatory anxiety which is often the most problematic –
- Shots hurt/sounds startling or hurt etc but if one is minimally anxious ahead of time and during, then these experiences are much more bearable

+ So how do we help people with WS relearn emotional associations?

- How does this learning and relearning that one can experience events without massive fear typically occur?
- Even ‘well regulated’ infants and toddlers, by nature are pretty dysregulated and have many fears.

+ To develop decreased fear responses, typically developing infants and toddlers use

- Social emotional cue reading of
  - Tone of voice, facial expression, body posture etc of caregiver
  - In addition to self soothing
- Pretend play to play through scary events (doctor visits etc)
- Conversations with adults and each other

+ These tools for developing decreased fear are later developing or less fully developed in many people with WS

- Young children have diminished early language and pretend skills that typically developing children use to decrease anxiety and develop anxious responding patterns
- Diminished “Executive functioning” abilities in older kids/adults make it harder to envision ahead; plan and use strategies; regulate emotions

+ Why is anxiety so prevalent in people with WS? A (hypothetical) Neuro-developmental model:
But the good news is that with adult scaffolding/with treatment...

- People with WS can generally use these tools of co-regulating with adults while practicing experiencing feared event in small manageable amounts.

Blood Pressure taking phobia

- 6 yr old boy with Williams syndrome
- His of cardiac surgery and monitoring –
- Frequent doctor office visits required
- BP read never been obtained except under sedation, as child too distressed, prior to treatment
- Mother described upset level as 10 on 1-10 scale ("extremely upset, screaming, crying, physically protesting")
- Hospital had given family a home BP kit but once he saw what it was, even when they brought out the case, he became extremely distressed, so they couldn’t use it to practice or take his BP
- Language/cognitive delays and no spontaneous pretend play – so natural regulating mechanisms compromised

Treatment process

- 1 ½ hour play session with mother, child and me at the WSA 2010 convention in St. Louis
- Mother conducted 4 similar follow up play sessions at home
- Mother described play sessions as enjoyable

Videoclip

Following treatment

- Mother described his presentation when having BP checked as a 5 ("mild upset; protests but goes along")
- Mother reported that an accurate BP read is able to be obtained
- Effect continued at 2 and 4 month follow up communication with mother
Now to back up a little

This model is a bit different from how phobias are usually treated

Traditional therapies for anxiety in the general population...

...in GENERAL are reliant on a level of language, social interaction, and metacognition not accessible to most children and many adults with WS

So there is a common, often chronic occurrence of anxiety in various forms, with well-established treatments, that are inaccessible to this large population

Cognitive Behavioral Therapy (CBT)

The most widely established treatment for anxiety/phobias in typically developing children

Requires a fairly high level of language, executive functioning and metacognition

Some teens and adults with WS can access and benefit from CBT

Many therapists are trained in CBT

How IS anxiety treated in people with DD?

Treatments are generally behavioral in orientation

This can overlap with CBT in how it “looks” (e.g., reward for increasing exposure to feared object results in exposure/decrease in anxiety) yet the understanding of “why” is different (e.g., child may be seen as noncompliant rather than as phobic).

The graduated exposure process as it is done with kids with DD often involves child distress - then attenuation

Why are there few treatments for anxiety for this population?

Paradigm / ‘culture’ differences

In DD world, anxiety symptoms are often viewed

As behavioral problems

Similar to other forms of noncompliance/avoidance

And/or as “part of the diagnosis”

Not warranting specific treatment different from other components of the diagnosis

I see that view as very wrong because phobias

Both are often quite debilitating

And often can be effectively treated

And can often be treated in ways that are fun

Other anxiety treatments often used

Positive behavioral supports (PBS, Koegel, Koegel & Dunlap, 1996)

Sensory integration

Teaching key functional communication (Total Communication)

Multiple uses of visual supports

Visual Schedules / Social Stories TM

Environmental Adaptations

Psychopharmacology

Exercise

Cognitive Behavioral Play Therapy (CBPT, Kneb)
Phobia myths!

Myths about anxiety and treatment

- If you don't tell a child in advance about something they generally are anxious about (e.g., Drs. Appointment) they won't worry about it – telling them makes them anxious.
- While it's true they won't be anxious beforehand, as they don't know what's about to be 'sprung on them', they and you don't have a chance to to the prep work so anxiety is unlikely to attenuate.
- Just telling with no prep work is likely to increase anxiety.
- Springing things on a child can lead to child more anxiety about unexpected surprises – may not trust you about upcoming events, may seek more and more reassurance (no fire drill today right?).
- Of course you have to use your judgment – don't tell a week in advance if it will ruin the whole week etc.

Myths continued

- Exposing the child to gradually longer amounts of time to the trigger situation (stay 2 then 3 then 5 minutes in cafeteria) is the primary way to decrease anxiety.
- Sometimes...
  - The "whole situation" may be too intense even for short times, for anxiety to decrease.
  - Each exposure can cause increase in fear response.
  - We'll talk about "unbundling" phobias into separate components.
  - Combining these with anti-anxiety activities.

Myths continued

- Telling a child something they are scared about is "no big deal" is reassuring.
- Sometimes – not usually – sometimes for issues that the child generally is able to handle well.
- But if for that child it feels like it is a very big deal unlikely to help.
- Consider an adult afraid of public speaking who has to give a presentation or afraid of flying who has to take a flight – imagine if telling them it's not a big deal would be helpful.
Myths continued

- Anxiety can’t be a cause for a behavior that only sometimes occurs in reaction to a situation and sometimes the person is fine with it.
- Baseline anxiety levels fluctuate sometimes day to day, week to week – if a child faces an anxiety provoking situation in a happy low anxiety state and has good ‘co-regulators’ with them they are likely to be less anxious.
- Subtle differences in situations that appear the similar may impact anxiety (e.g. assembly with music vs assembly with people in uniforms; assembly that changes a key part of a schedule for a child vs assembly that does not).

People act afraid to avoid doing things that are hard for them.

- Possibly – sometimes
- Most children would rather not be afraid of the things that make them afraid.
- Older children and adults are generally very articulate about this (“I wish I could just… without being so afraid.”)

How to treat phobias: The basic model:

- Create a series of
  - of gradual/tolerable levels of exposure
  - To each component of the feared event
  - While accompanying each level of exposure with something that specifically helps the child to decrease their level of potential distress
- Adjust exposures based on child response –
  - make sure level of anxiety is not unpleasant
  - Make sure child is connecting exposure to actual event

Continually adjust exposure level and anti-anxiety measures based on the person’s emotions:

- Person should be
  - INTERESTED and increasingly participatory in what you are doing +
  - And not unpleasantly SCRARED by what you are doing.
- Adjust level of realism
- Adjust anti-anxiety measures
- Especially consider ways to add socially connected humor, a strong anti-anxiety measure for most people with WS.

The specific components of a phobia that cause fear vary somewhat for each individual.

Consider

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The 4 Steps

Step 1: Figure out key "trigger components" of the feared issue –

"Unbundle" the phobia

Step 2: Design levels of gradually increasing exposure to each component

Step 3: Determine activities, that reduce the person’s anxiety

Step 4: Do each Level from Step 2, combined with anxiety reducing strategies from Step 3

Step 1: “Un Bundling” the components of the phobia

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Other components causing fear...

- One often can’t figure out all components tied together in a “phobia bundle”
- Some components may have been outgrown in some circumstances but continue when in a specific phobia bundle (e.g. child may have good pain tolerance for the amount of pain of a shot but still be afraid of the shot as it is tied to overall “shot phobia bundle”)
- Use those components one can figure out and desensitize separately and together

Step 2 Figure out ‘Levels’ for gradual exposure to desensitizing the person to each of these components

- Sometimes called “Fear ladders”
- Can involve
  - Pretending parts or all of the component(s)
  - Video (Youtube; Home made)
  - Role play
  - Audio
Example of Step 2

Designing levels of gradually increasing exposure to each “unbundled” component

For Fear of shots

Sample Desensitizing activities (specifics based on child)

- Without the child, make a video of going into the doctor’s office. Make it funny (e.g., include figures child likes).
- Schedule non-appointment visits. Keep them short and pleasant. Give child a job (e.g., to give the receptionist something), have child bring favorite toy.
- Have child meet those who will be at the visit if possible.

Sample Desensitizing activities (specifics based on child)

- Start with toy doctor materials and favorite figures (e.g., stuffed animals/legos/etc.) OR start with one piece of real material (e.g., tourniquet) on self.
- Play giving shots to figures or self with making the figures or self playfully little scared.
- Increasingly incorporate more real materials into this play on self, figures, siblings, and have person with WS give you shots with the materials.

Fear of medical materials involved (e.g., tourniquet; syringe; alcohol wipe)

Sample Desensitizing activities (specifics based on child)

- Find YouTube clips of people getting blood draws, some when patient looks scared some when patient doesn’t.
- Make video of self or other beloved people getting actual blood draws. Act clearly playacting, a little scared. Add humor.
- Incorporate playful versions of fear into all role play of the activity.

Step 3: Figuring out strategies - self and/or co-regulation strategies - to DECREASE the child’s distress - to use while INCREASING exposure

- Varies for each individual and situation what is going to be relaxing and that the person can access during the exposure activities and during the actual feared event

Co-regulating strategies

- Those done with another person
  - Often especially effective for people with WS
  - Interactive humor about the event
  - Interactive humor about fear itself (playful exaggeration together)
  - Interactive role play
  - Videos of a favorite person doing the event, with humor (e.g., sibling or friend goofing around on escalator or during blood draw or during alarm going off)
  - Company/physical comfort
**Self regulating strategies**

**Relaxation practices**
- Guided meditation type, with voice very useful – can download these or read or make them up and record them onto iPod/phone
- Many people with WS especially auditorily suggestive and able to relax this way
- Yoga
- Dancing
- Sensory tools (OT helpful here)
- Music – especially helpful for many with WS
- Other – electronics-games/pets

**Co- and Self – Regulation Strategies**
- Often self-regulation strategies are most useful to reduce baseline overall anxiety – may be most useful in advance of exposure
- May be hard or impossible for individual to access during actual exposures until their anxiety is reduced
- Co-regulation strategies are often most effective to reduce anxiety in the moment of increasing exposure
- Co-regulation often more helpful than self – reg for children and for people with very high anxiety
- **Rule of thumb:** Try and see what works to decrease anxiety for this person/situation

**Step 4: Do each Level of gradual exposure from Step 2, combined with anxiety reducing strategies from Step 3**
- Continually adjusting based on person’s response
- If person is afraid,
  - Move to less realistic level
- You can add new in-between levels
  - (more role play; pretend; break down a component)
- Add anti-anxiety measures
  - Add more humor; have person be more in control
- If person doesn’t seem to make the connection between what you are doing and the real trigger
  - Move to more realistic level

**Dentist visit prep example**
- Last time had cried and stood in doorway
- Did play like in next clip many times with parents and me and dolls
- Watched youtube clips of child dentist visits
- Mom brought our funny play on phone to exam where child watched it
- Then had a fully successful dental exam

**Dentist and fear playful video clip**
+ Monitoring impact
(Practice Based Evidence)
- If not working consider ways to 'sinker'
  - More or less realistic depending on
    - Level of symbolic understanding
    - Degree/nature of adult affective engagement
    - Add video/realistic photos/sound effects combined with favorite music etc.
  - Consider if there are other components not being addressed

+ Simpler version for younger kids or kids with less symbolic understanding
- Playful affective reflection:
  - Simple often effective re sensory fears (e.g. balloons/sand/sunscreen/foods etc)
    - Adult touches just barely saying "yucky yucky" pulling hand away quickly and
      - Smiling
      - Child looks/laughs
      - Adult does it again (and again and again) waiting for child's look and laugh each time
      - Often child ultimately joins in

+ Does this always work? No.
Barriers may include
- Biological component(s)
- May need tools needed first to reduce baseline anxiety
  - Sleep; exercise; sufficient control overall; sufficient successes overall
- Multi-factorial nature of response pattern
- May have missed components bundled in the phobia
- Step increase in anxiety may be too steep
- May not have enough anti-anxiety tools
- Medication may be needed

+ A bit more on use of technology, both to create exposure levels and incorporate co-regulation

+ Most experiential phobias one can find 
  Youtube or Vimeo ‘help’ for more help with in between steps/gradual exposure!
- Medical procedures – check ups, blood draws
- Birthday parties
- Haircuts, nail clippings
- Fire engines, fire alarms, ambulances
- Automatic flushing toilets, vacuum cleaners, hand dryers, weed whackers
- Thunderstorms
- Crying babies

+ Ways to use video clips
- Find just where the scary parts are so you can turn volume down/earn child
- Watch them slowly as ‘stills’ with the child or with no sound
- Make the sound yourself but in a funny way with the volume off/low
- Warn when sound will be coming – ask if child is ready –
- Use a rhythmic chant together “Ready ... set... BOOM” for thunder video
- Have child use drum or symbols to make loud sound at the same time as in video (Here it comes ready GO!!)
- Use them together with pretending once person is used to them (watch the thunderstorm video together outside at night)
Note re youtube

- Don’t search and try clips you haven’t yet watched, with children there!!
- One never knows what inappropriate clips or previews will come up from any search term
- Find them and screen them first

Apps and sound sites

- Many great apps for desensitizing
- Toca Boca doctor, Toca haircut
- Toca Kitchen for electronic sounds like microwave, blender
- My PlayHome app has each room of house with sounds (e.g., toilet flushing, shower etc)
- Sound Apps Balloon Popping, alarms, whistles
- [http://www.soundsnap.com/](http://www.soundsnap.com/) audio of everything in many versions – short, predictable – helpful to find just the version of the sound you are looking for if you can’t record it
- Several bugs and bees games

Can easily make individualized funny clips to desensitize

- Clip of child’s favorite superhero, rock star, boss, parent, coach, being ‘afraid’ then OK on escalator/listening to sounds/having medical procedure
- Clips/audio combining what child thinks is funny with feared sound etc

Slurping scoreboard buzzer sound

Summary

- Many phobias can be successfully treated in children and adults with WS
- The treatment process itself can be a fun and bonding experience
- Working collaboratively with Counselors, OTs, SLP, teachers, behavioral specialists is often very helpful
- These steps aren’t always of course successful or fully successful, but usually at least provide a medium for dialogue about the fear
- Medication can also be used and can be used together with treatment

Questions…