

Embracing Uncertainty or at Least Tolerating It:

Talking to Kids and Teens About Not Knowing

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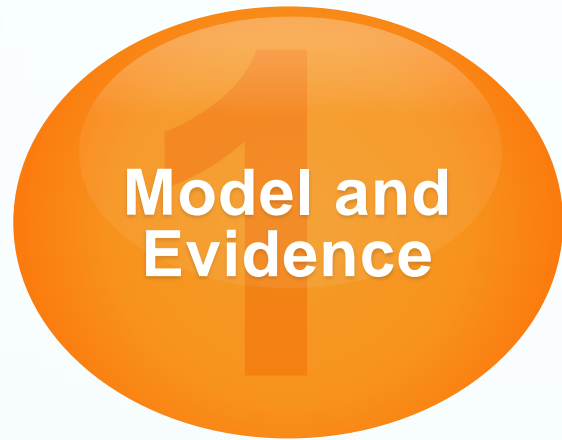
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- No conflict of interest with the content of the presentation.
- Receive royalties as an author of treatment program listed as a resource.

Objectives





CBT Model & Evidence

Factors related to the
development and maintenance of IU

The CBT Approach to Anxiety

- Psychoeducation about nature of anxiety – goal is to make everyone an expert.
- Three part model- how anxiety makes your body feel, how it makes you think, how it makes you want to act/
- Recognize and label anxious thoughts and challenge them.
- Face feared situations gradually via exposure.
- *More work recently about the NATURE, PROCESS, and REACTION to anxiety and less on specific content*

What is Intolerance of Uncertainty?

Intolerance of Uncertainty

- “The belief that it is absolutely necessary to be certain and that if one cannot be certain, then one will find it **impossible to cope**; often related to overestimation of threat and fears about responsibility.”

Bennett-Levy et al., 2004

- A belief system where uncertainty is viewed as stressful, upsetting, unfair, negative, and should be avoided

Buhr & Dugas, 2002

Intolerance of Uncertainty Across the Anxiety Disorders

- OCD
 - If I don't say my prayers perfectly, I will go to hell.
- GAD
 - What if my sore knee is really bone cancer?
- Separation Anxiety
 - What if something bad happens to mom?
 - What if I can't manage my anxiety when I am at the sleepover?

- Social Anxiety
 - What if they laugh at me?
- Specific Phobia
 - What if the dog bites me?
- Panic Disorder
 - What if I faint during my chorus concert?

- A common thread we see across the anxiety disorders is discomfort with uncertainty/not knowing.
- This discomfort leads to distress and avoidance of situations.
- This informs treatment –
 - Probability of “bad things” happening is slim.
 - In order to live our lives, we have to accept uncertainty.
 - We have to build within our patients the idea that they could cope if bad things did in fact happen.

What IU Looks Like Clinically

- Anxious kids....
 - Always ask, “What if?”
 - Ask questions over and over again to be completely sure.
 - Want to know the plans, and don’t do well with changes in routine or plans that are “up in the air.”
 - Are often afraid of “new” things because they have no data to go on.
 - Have a rough time with times of transition (new school year, new school, going to college....)
 - Can be rigid with rules for what they wear, what they eat, how they play games, etc.
 - Doubtful of own coping abilities.

OCD approach

history of this approach

- A thought is just a thought- nothing more or less
- Brain glitch – not of meaning - don't own it
- Agree or go with doubt – maybe it's true maybe not
- Risk taking to see that dreaded consequence does not come true if don't do ritual
- Exposure- face feared situation in vivo or imagination
- Response prevention- delay, change and eventually eliminate rituals
- Want to know belief or ritual to design exposures but the content is not that important

Intolerance of Uncertainty and Related Concepts in the Other Anxiety Disorders in Adults

- Adults with GAD are higher in IU than that seen in other anxiety/mood disorders (Buhr & Dugas, 2006; Dugas, Buhr & Ladouceur, 2004) □
- Changes in IU precede changes in worry in treatment (Dugas et al., 2004)
- IU also present in other anxiety disorders (e.g., OCD, social anxiety, health anxiety)
- Likely transdiagnostic- also anorexia, depression and pain

Data on Intolerance of Uncertainty in Youth

- Anticipated distress and threat interpretation were specifically associated with anxiety symptoms (Creswell and O'Connor, 2011)
- Children ages 6-10 were able to describe positive and negative beliefs about worry including intolerance of uncertainty (Wilson and Hughes, 2011)
- Intolerance of uncertainty associated with perfectionism, anxiety and worry in teenagers (Flett et al, 2013)

Uncertainty driven coping approaches

- Attempt to reduce, avoid, or circumnavigate uncertainty
- Reassurance seeking
- Information seeking
- Excessive list-making
- Doing everything yourself (refusal to delegate tasks)
- Double-checking
- Over-preparing



IU-Driven Avoidance Behaviors

- Avoidance of novel/uncertain/ spontaneous situations
- Procrastination
- Maintenance of a predictable routine
- Asking others to make decisions for you
- Impulsive decision-making
- Distraction/keeping busy

Talking to Kids and Teens about Tolerating Uncertainty

The problem with worry/anxiety

- Worry takes time and messes with fun
- There are things to prepare for and things not. So much time thinking about worst thing you don't prepare for likely
- All those bad things makes you think about makes you upset and is usually SO wrong
- Best things can't prepare for – falling in love, who friends are, best times with friends“
- Parents should provide routine because everyone likes predictability but expect child to cope with change
- “planned sabotage”- help families be flexible and catch moments of “flexibility”, do things out of order, dinner for breakfast, switched up Saturday

Approach to uncertainty

- All our brains like info and to know what is going to happen
- Your brain especially does not like not knowing, not knowing the plan or not being sure
- You are going to feel a lot better if we help you get more used to not knowing and that things are ok even if you do not have a plan
- We are going to start with easy examples
- For teens – I say you are going to probably hate this but I going to help you at least tolerate uncertainty and hopefully to embrace it

Kids and teens coping overall

- I am not in danger I am just feeling really scared
- This is worry, fear, anxiety, stress..... nothing more or less
- This bad feeling will pass
- There is nothing special I have to do
- Don't add to it with anxiety tricks
- I like it better when I know but I don't have to know to be ok
- Don't avoid





Strategies for Intervention

Key Interventions

- Psychoeducation (covered in Section #1)
- Talking about anxiety in a different way (this is our cognitive work)
- Testing out our beliefs (this is our behavioral work)
- The big picture – thinking about coping, quality of life, etc.

Behavioral experiments

Testing out beliefs about situations that have uncertain outcomes:

- What is my feared outcome? How likely do I think it is that this outcome will occur?
- What actually happened?
- Was I able to cope if the outcome was negative?

Why are B.E. different from coming across feared situations before?

- They are planned.
- We make predictions and evaluate them once we are done, like scientists.
- The goal is learning.
 - This is our cognitive work – we learn to think about feared situations in a different way.
- We approach them with a toolbox of strategies.

Strategies



- No emergency here, send the fire trucks back to the fire station.
- Surf the urge to do rituals/safety behaviors.
- Shift focus of attention from internal to external.
- Get busy with something else while the anxiety is doing its thing.
- The more you do it, the easier it gets.
- If we get repeatedly approach situations NOT NEEDING certainty, uncertainty becomes easier to handle.

Going into Exposures

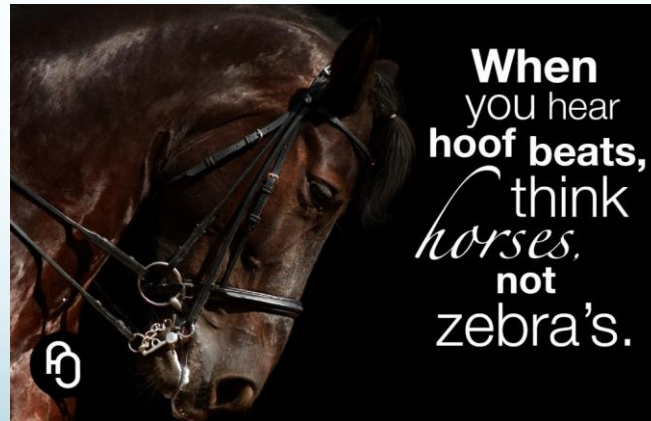
- Know Thyself!
 - Anticipate anxiety reaction
 - “Oh No” or “No I am not going”
 - “It’s my new thing thing” – my change thing
- Cultivate a second reaction- not my final answer
 - I don’t like change, but I can handle it
 - I wish I could know, but it is not necessary for me to be ok

Examples of Exposures

- Stand with coat on for 45 minutes to see if you will faint.
- Walk through city past street people to see if “bad things will happen.”
- Wait with friend and friend’s mom while mom parks at ski lodge to see if mom comes back/is okay.
- Go on train to D.C. and see if the train gets stuck and you never get home again.

Big picture “stuff”

- Needing certainty takes time and messes with fun.
 - What kind of life do you want to live?
- Needing certainty makes you focus on all the things that are highly unlikely to occur.
 - Are you spending enough time focusing on things that are very likely to occur?



- Needing certainty has us stuck in the future, in the what if's.
 - Are you missing out on what is happening here/now?
- We actually can't prepare for the best things in life – falling in love, who our friends are, adventures on trips, etc.
 - If we had certainty or “knowing” about these things, they wouldn't be nearly so special.



vs.



Mini-Case - Jane, age 16

- Presented for treatment following history of bullying at old school and extreme anxiety at new school.
- 10th grade, very gifted student at private school. Lots of talents, very busy, very hard working.
- Only child of stay at home mom and engineer dad. Very close, understanding family.

- Started 9th grade at new, competitive private school.
- Got bullied, socially ostracized – mostly revolving around being smart.
- Parents decided over summer to switch schools to another private school, back with grade school friends.
- Presenting problem –

“What if it happens again?”

Beliefs

- History will repeat itself.
- I don't know who to trust/who my friends are.
- If people knew my real grades, they will reject me.

Core belief: If people really get to know me, they won't like me.

Therefore, Jane was keeping to self, not making new friends, lying about grades, and begging teachers to not announce grades in class.

Another Source of Uncertainty

- What if I faint in front of others?
- Speaking in class?
- Singing in liturgy?
- Singing at Epcot?
- Safety behaviors
 - Seek reassurance from mom.
 - Eat right before show.
 - Have water at all times.
 - Dress in cool clothes regardless of weather.
 - BIG temptation to avoid.

Strategies re: Fainting

- Did very minimal education.
- Look at the evidence – hasn't happened before, so likely not to happen.
- BUT, discussed accepting uncertainty.
- Examined cost and coping – if it were to happen, would it be so bad? Could you handle it?
- Importance of dropping safety behaviors.
- Taught how to shift focus of attention.

- Interoceptive exposure – stood in living room with winter coat on every day for 45 min (length of concert).
- Exposure, exposure, exposure!

Strategies re: School worries

- Accepting uncertainty
 - We have no control over what people think of us.
 - We aren't mind readers.
 - If you are “yourself,” some people will like you and some won't.
 - You can “reject” people too.
 - It is possible you will be rejected again, but given all accumulated evidence, not likely.

- What can we control?
- We can choose to live a life of meaning.
- What is important TO YOU? What do you want others to see/know about you?
 - ***** Grades/smarts – finding like-minded friends.
 - Music – in school musical despite time away from studies.
 - Friends – trying to share more, be more authentic.

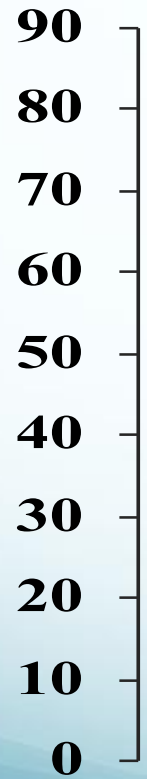
Academic Perfectionism

- School achievement is very important to Jane but she over-prepares and over-studies to the detriment of sleep and leisure time.
- She internalizes school messages about studying more and working harder, but these messages are not for her.
- Her project is different – work less and see what the outcome is.
- This is rife with UNCERTAINTY!
- Assignment: Take a school-related risk every day and see what the outcome will be.



Working with Parents

We've tried everything, nothing worked!



Developmental Model

- Anxiety is maintained through avoidance, escape and withdrawal
- Intolerance of uncertainty is partly maintained by parent factors:
 - Modeling/reinforcing avoidance
 - Rescue from negative outcomes, removing demand
 - Rejection/negativity
 - Overcontrol/overplanning
 - Inconsistent Contingencies

Every time you respond to anxiety by providing relief or by facilitating avoidance, you deny your child two essential learning experiences:

1. Anxiety goes away on its own without doing anything.
2. Uncertainty doesn't mean bad most of the time - Feared consequences are highly unlikely to occur, and whatever happens, your child can handle it.

New language

- Restate and acknowledge (show empathy) without providing reassurance or getting into problem-solving:
 - It sounds like the alarm is going off really loud right now.
 - I can see it feels really bad to feel so uncomfortable.
- Communicate confidence:
 - It's tough but you're tougher
 - I'm not sure, but I bet you can handle whatever happens.
- Keep it short:
 - Why don't we wait and find out when we get there.
 - We won't know till we go.
- Communicate your values and expectations:
 - It's really important that we go (try, handle responsibilities, show our support, etc.)
- Set limits and give opportunity to approach:
 - We'll need to finish before we can... but I'll give you a minute to get things going...



Set clear limits

- Parents fear that their child is too delicate/can't handle rules and limits.
 - However, children thrive on rules and consistency.
- Anxious children actually feel scared of the power they yield in the family.
- They want to give power back to their parents.
- When parents let their kids avoid, kids get the impression that their parents think they can't handle tough situations.
- Kids thrive when they see that they can succeed in difficult situations.
 - SO, when the therapist says, YOU WILL BE ABLE TO X, wow, it is empowering!

Exposure to Uncertainty

“Make a bad thing happen”

- If you catch this...
- Let's kill off your whole family! (exposure to death/loss content)
- “I the All Powerful Ursula put a curse on you that no one will ever be your friend again” (exposure to rejection content, younger)
- It's definitely going to happen this time (jinx/“what if” exposure)

I'm not sure but...let's try it

- Leave backpack at home (lose points/get in trouble, unknown negatives)
- Don't know the day's agenda (could be boring/uncomfortable)
- Sign up for an activity that you are novice/not skilled (exposure to imperfection, uncertainty, negative evaluation)
- Take time to order, then change your mind (awkward/uncomfortable, uncertain social outcome)

Adopt a “Coaching” Style

- Parents demand, coaches train
- Evaluate the situation realistically, plan for success
- Focus your child on what they know and successes from the past
- Not time for challenging anxious thoughts (“keep it short”), instead, ask “Anxiety is trying to get your time. How will you ignore it? Let’s test it out and see what happens.”
- Give opportunities for practice, but no surprises!
- Reward (praise) all efforts, no matter how small
- Remove safeties, do not reinforce avoidance (watch out for negative *and* positive reinforcement)

What is most difficult for parents?

- Letting the child fail/ struggle
 - Mistakes promote learning and mastery
 - Fear that “situation X is too important to fail”
 - Parental “overprotection trap”
- Limits progression towards independent coping



Parent anxiety or discomfort with exposure?

- Meet to discuss beliefs about anxiety and tx
- Shadow an in-session exposure
- Be explicit how to take *in vivo* home- what, when, who
- First time should be simple, what was practiced in-session- make sure going to be successful.
- Prepare for reaction: likely difficult at home especially at first-extinction burst
- If can't do planned exposure, "what CAN you do?"

Decision making

helping with coping or helping anxiety?

- Accommodation is short term step toward goal of coping or independence
- The help is support of coping strategy use
- The help is in service of guiding self soothing rather than others providing the help or reassurance
- Know important aspects of routine and expectations
- Adjustment to new things or transitions-break down step
- Is the behavior responding to or listening to anxiety rules
- Does the child say has to have it to feel ok or function
- Is it used only as a way to escape anxiety or in moment of anxiety
- Is it out of the realm of normative for other kids
- Ask and need to know all details before goes or tries each and every time

Case Example

- 12 yo male & 14 yo female with panic and school refusal
- Diagnosis: Panic w/Agoraphobia
- Treatment Focus
 - Increase structure, behavioral requirements and consistency
 - Interoceptive, in-office, community, in-school daily exposure
 - Collaboration w/school for gradual re-entry
 - KEY FACTOR: Parent's stance

Family uncertainty about anxiety and belly pain

- 8 yo referred by pediatrician
- Concern about belly pain, and worry
- frequent trips to bathroom and concern will be sick if cannot go- never happened
- However recently threw up at night and felt scared
- Interesting stressor- family put in Christian school and lot of talk about Satan and devil. Confusion God is my father – I thought my Dad was my father
- History of separation anxiety for parties/activities

Belly and other problems

- Intruder drill – she was in bathroom - surprised
- Gone to nurse 30-40 x by April
- Week before I started school nurse and school staff with mom gave her reward for not going to nurse
- Excited about plan – did well for a week and then had emotional breakdown for 2 hours- hard week for her, nowhere to turn, hard not to go to nurse
- Mom very upset by this – promise to help her, insist will go to belly doctor
- However next day child handled a fire alarm wonderfully and proud of herself for coping

Current worry rules

- Goes to bathroom

when wakes up, after breakfast, when she arrives at school, other trips during day and after lunch

- Wants to limit car rides overall
- Hates to be late or wait because interferes with access
- Beginning to limit what eating

Parent concerns

- Mom really wants to be a good and supportive mother-frequent email questions
- Her mom very rigid, never able to please always trying – sought therapy for herself 16yo- work on boundaries-
- Mom hx of anxiety and depression
- Dad anxiety and irritable bowel disorder
- Parents very anxious to do right thing
- Both felt did not have good parent models-
- Did not want to have daughter feel were not believing or taking seriously

Coping with discomfort

- Stomach bothers you when- drives, have to wait
- Fears if don't go – get sick or hurt more
- Coach mom to coach her then self soothe
 - it's just a feeling – not an emergency
 - we can stop if we have to – but probably won't need it
 - plan to wait 10 minutes- eliminate certain bathroom trips
- Experiments if worry is correct- do you get sick or get worse if wait to go – do something else and see it passes

What really scares mom not eating

- Lots of anxiety about eating
- Limit eating at home- eat very slowly
- Not want to eat away from home
- Feels first bite makes her belly hurt
- Ask do I look pale?
- Really focused on healthy and unhealthy foods



Boss back to eating

Worries

- It is going to hurt
- I better not throw up
- I cannot eat I am too full

Boss back

- My warning alarm is broken
- First bite just makes me feel full
- Not really full I am getting used to eating
- It is safe to eat

Help parents not knowing

- Medical or not or both- often can't fully separate
- Still helps to find out
- Limited time frame to see if she gets better with behavioral- if so not medical
- If does not get better- more likely physical
- Parents very anxious but with support found very hard to do but proud of themselves for doing it
- Collaborating with pediatrician who felt GI consult still important

Eating plan

- Parents to remind her of steps before eating
- No talking, yelling or reminding of food at meal
- Options of word games, drawing or reading while eating at breakfast and lunch
- Not at meal time remind has to eat for energy
- If did not eat – plan to lie down until she ate for energy
- Doing really well- eating more regularly not complain belly pain
- Mom realize has to do with how she is doing- meditating herself every day- feels empowered

Follow up



- Eating better
- Not complain of pain
- Mom and her going out to eat
- Mom goes away for weekend with friend and family survives and child eats
- Not scared about eating at school
- Pediatrician in consultation still feels concern fullness, excessive burping, some pain and family history
- GI consult starts lepsin anti spasmodic tx 6 weeks for IBD and continue Xantac also helps her to eat more comfortably

Case Example

- 11yo school refusal
- Presenting: “Happy” “Normal” no hx of anxiety. Complains of headaches, “irrational behaviors,” “shut-down” in anticipation of school and/or new/unfamiliar social situations. Poor nutrition (picky eater).
- Maintaining factors:
 - Parents unsure if fatigue/shut-downs are from “real” headaches or poor nutrition.
 - Afraid to push – don’t want to trigger “shut-down.”
 - Unsure if the anxiety is “out of his control” “too much for him to manage”
 - Needs “strategies”

- Individual work: Psychoed about anxiety, somatic sx (possible link to headaches), to challenge anxious thoughts, boss back the anxiety, and plan behavioral experiments.
- Work with parents:
 - The work may fall on them – he is not interested in tolerating uncertainty or discomfort.
 - Set clear expectations and limits
 - Tolerate shut-downs and not eating well
 - OK to demand – he can handle it.
 - It's not that he will use strategies, feel better, and then do the thing, it's that he will “be reminded he has strategies, do the thing (over and over), and then feel better
 - Stop reinforcing avoidance (limit reassurance, safety behaviors, attention during “shut downs”)

Resources

- www.worrywisekids.org
- www.CopingCatParents.com
- Anxiety Disorders Association of America
www.adaa.org
- The International OCD Foundation:
www.ocfoundation.org
- Association for Behavioral and Cognitive Therapies (ABCT)
www.abct.org



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