ACT and Tourette’s for Parents

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The Plan

Why use ACT?

Basic loop of Tourette’s/Tics

Shared mechanisms

Building flexibility

Increasing committed action

Using present moment awareness

Role of defusion
What is ACT?

Acceptance and Commitment Therapy
(Pronounced “act” not “A-C-T”)

- Emphasizes present moment awareness and acceptance
- All behavior has a purpose even if not adaptive
- Behavioral flexibility vs rigidity
  - Ability to take a new route
  - Brain likes familiar roads
- Values-aligned action
  - Being the kind of person you wish to be
  - And forgiving yourself when you can’t
Parallel Process with Parents and Children
1. Child learns to manage tics
2. Parent learns to manage self

Self-Care = Other-Care
(Pouring from empty cup metaphor)
1. Acknowledge own feeling and need
2. What you wish for your child
3. Anxiety about your child’s future
4. Self-judgment and criticism
Accepting our own emotions...

*(Emotion akin to premonitory urge)*

1. Acknowledge own feelings and needs
   1. Frustration
   2. Concern/Worry
   3. Desire to protect child

2. What you wish for your child
   1. In the present
   2. In the future

3. Self-judgment and self-criticism
   1. Blaming one’s self - because self is something can act upon
   2. Criticizing own responses in the past and present
Getting out of our own way (cont.)

... in the service of others

(Committed Action like Competing Response)

1. Love and Care
   1. If you didn’t care, you wouldn’t be stressed!

2. Compassion and Bond
   1. Parent-child bond helps child’s anxiety
   2. Focus on compassion as worthwhile goal

3. How does emotion serve you?
   1. Motivation for action
   2. Warnings for future action
   3. Modify/revise own response
   4. And sometimes it doesn’t!
How does TS affect your child?

Helps to “get real” with self

1. Social effects of TS
2. Co-occurring challenges (inattention, anxiety, anger…)
3. Medical impact of tics
4. What else have you noticed…?
Applying ACT to Self

Noticing, Anchoring, Choosing, Doing

1. Recognize when our emotions aren’t helping us much
2. Accept that they are there even if not helpful
3. Practice pausing to bring mind back online
4. Notice what feel like doing
5. Then choose what will do
6. Engage in action even if feels odd or difficult
7. (Celebrate and congratulate self!)
Applying ACT to Tourette’s

Adding ACT to enhance treatment

1. Increase engagement
2. Manage distress and frustration
3. Improving quality and satisfaction in life

Doesn't replace existing treatments
More like a flavorful spice to enhance it!
Why ACT?

Tics are a behavioral phenomenon:
- Maintained by negative reinforcement
- Highly rigid pattern of behavior

Addressing tics is uncomfortable:
- Build resilience through acceptance
- Aversive covert events (Urge) may persist
- Defusion to target distress
- Decrease functional impairment, increase life satisfaction

Enhance other methodologies with ACT:
- ACT alone not likely sufficient
- Related disorders show promise with ACT-enhancement
ACT-like Approach

The Cognitive Psychophysiological Approach to Tics (CoPs)

- Emphasizes acceptance
- Addresses context in which tics occur
- Aims to promote flexibility of behavior
- Teaches client to move toward personally-meaningful goals
- Uses interoceptive insight
- Separates treatment compliance from change
- Views non-compliance as “learning opportunity”
Basic Loop of Tourette’s

Context (as a bubble)

- Time
- Place
- People
- Activities
- Emotional State
- Physiological State

Urge->Tic->Relief

See as narrow responses
Class exists within bubble
**Contextual Loop**

### Context
- Pressure (Internal and External)
- Heightened reactivity
- Reduced inhibitory mechanism

### Manifestation of response (tic)

### Change in Context
- Momentary reduction
- Engagement in action
- Discharge of tension
Shared Mechanisms

- **Negative reinforcement**
  - (Context) Urge -> Tic -> Relief -> Repeat

- **Problem-solving process**
  - Problems produce “discomfort”
  - Covert response

- **Discomfort as motivator**
  - (Is *everything* negatively reinforced?!)?
  - Actions learned to reduce discomfort

- **Pattern identification**
  - Human learning
  - Relational framing
In moment between Urge and tic – add a link to the chain

Awareness of Urge – seeing for what it is

Choice as alternative behavior

Urge works as an indicator to use competing response

Choice functions as a new link that then leads to other behaviors

Target behavior (tic) remains a choice

Allow child to choose response as long as it’s intentional
Increasing Committed Action

In presence of discomfort

Increase follow-through/treatment compliance

During practice sessions
- Can use non-tic (classic ACT) practice first
- Focus on foot -> mind wanders -> notice and return to foot
- Begin to integrate into tic-related experiences

Child-identified outcomes
- What think may happen
- How it feels to imagine the experience
- How expect it may feel for real
- Helps get ready for harder practice
Role of Defusion

1. Addressing social anxiety and stress
   - “This is a thing my brain does”

2. Noticing and accepting “just right” experience
   - Name it (facilitate awareness)
   - Acknowledge it
   - Accept it
   - Set it aside

3. Facilitating alternative responding
   - Decoupling behavior and Urge
   - Noticing and attending to Urge as a sensation
   - See brain’s response to Urge as natural
Resources

- Tourette’s Association of America (TAA)
  - Centers of Excellence
  - Provider Directory
  - Educational Materials
  - Professional Trainings
  - Patient Support (Individual and Family)
- Tourette’s and Tic Professional Consultation Group on Facebook: https://www.facebook.com/groups/220734949500807/
- Buffolano, S. Coping with Tourette Syndrome. New Harbinger.


