USING TELEHEALTH TO TREAT PANS/PANDAS: HEALTH AND BEHAVIORAL CONSIDERATIONS (Part II)

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Outcome Objectives

• Describe how to use telehealth to better understand the bio-behavioral presentations of PANS/PANDAS
• Identify two family accommodations and two secondary gains in family systems via telehealth.
• Make appropriate behavior therapy recommendations indicated by empirically supported practices
Diagnostic Terminology

- **CPAE**
  Childhood Post-Infectious Autoimmune Encephalopathy

- **PANDAS**
  Pediatric Autoimmune Neuropsychiatric Disorders Associated with Group A Strep

- **PANS**
  Pediatric Autoimmune Neuropsychiatric Syndrome
Current Collaboration - CPAE

**Required:**
Abrupt-onset (within 72 hours of infection/illness)
   Obsessive-Compulsive Disorder (OCD)
   +/- Restricted eating (ARFID)

• **PLUS** comorbid symptoms from at least two of seven categories:
  - anxiety (particularly separation anxiety)
  - emotional lability or depression
  - irritability, aggression, and/or severely oppositional behaviors
  - deterioration in school performance [related to attention-deficit/hyperactivity disorder (ADHD)-like behaviors]
  - memory deficits and cognitive changes
  - sensory or motor abnormalities
  - somatic signs and symptoms (including sleep disturbances, enuresis, or urinary frequency) (Swedo et al. 2012; Chang et al. 2015)
Etiology

- Postinfectious autoimmune encephalopathy
- Idiopathic psychiatric illness (OCD, anxiety)
- Neurological conditions (tics, chorea)
- Genetics
- Family stress, caregiver burden, accommodation
- Child secondary gains
Medical Assessment and Treatment

• **GOAL**: Reduce inflammation
• Tiered treatment:
  • Antibiotics
  • Nonsteroidal medications (ibuprofen, Naprosyn)
  • Prednisone (steroids used to treat inflammation)
  • Intravenous immune globulin (IVIG)
Current Collaboration – CPAE Center of Excellence

- Immunology
- Psychology/Behavior Analysis
- Developmental and Behavioral Pediatrics
- Sleep
- Child & Adolescent Psychiatry
- Gastrointestinal
- Basic Science/lab
- Nursing
“While underlying infectious and inflammatory processes in PANS and PANDAS patients are treated, psychiatric and behavioral symptoms need simultaneous treatment to decrease suffering and improve adherence to therapeutic intervention.”

Behavioral Assessment and Treatment

• **GOAL**: Reduce challenging behavior & improve appropriate behavior

• Treatments:
  • Empirically Supported Behavioral Interventions
  • Parental Management Training (PMT) and Support
Telehealth Services for CPAE Children and Families
Access to Telehealth Services

• Location:
  • Telehealth services at a specific site with equipment provided (i.e., pediatric practice, outpatient clinic, school district or classroom, etc.)

• Home:
  • Equipment must be available to the family
    • Desktop computer and monitor or laptop (or other device such as a tablet or phone - most effective with enough bandwidth for quality video capability)
    • Webcam
    • Headset (if available)
    • Internet access
    • Video conferencing software (e.g., Skype, Zoom, etc.)
Real-time Coaching and Therapy

- **Areas of Services:**
  - Play-based language interventions (McDuffie et al., 2013)

- Skill Acquisition: Teaching ABA principles for therapy via discrete-trial and play-based formats (Fisher et al., 2014)

- Teaching and coaching parents (homes) and teachers (schools):
  - How to assess and understand challenging behavior (self-injury, aggressive behavior, disruptive behavior, tantrums, etc.) (Functional Analysis or Functional Behavior Assessment)

- Implementation of behavioral interventions (e.g., Functional Communication Training, etc.) (Gibson et al., 2010; Lindgren et al., 2016; Wacker et al., 2013; Wacker et al., 2016)
Challenges with Telehealth Services

• To Consider:
  • Poor video or sound quality (poor quality, blurred screens, etc.)
  • Technical difficulties (internet stability, lack of technology in rural areas, insufficient speed to transmit video/sound streams)
  • Equipment capabilities (webcam that can pan and zoom to capture child moving and room for data collection as needed)
  • Comfort with the use of technology (parental comfort and ease to use tech and trouble shoot tech issues)
  • Coaching skills (the therapist’s ability to effectively vocalize and communicate strategies when unable to be present or model, etc.)
  • Administration issues (policies and permissions, HIPPA compliance, etc., to allow for telehealth)

• (Frieder et al., 2009; Gibson et al., 2010; Heitzman-Powell et al., 2014; Hay-Hansson & Eldevik, 2013; Wacker et al., 2016)
**Treatment Acceptability summary**

Treatment Acceptability Rating Form-Revised (Reimers et al. 1992)

**Acceptability Data (n = 29)**

$M = 52.97; SD = 9.66; Range 31-67$

<table>
<thead>
<tr>
<th>Item</th>
<th>Question</th>
<th>$M$</th>
<th>Range</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>How acceptable do you find the treatment to be regarding your concerns about your child?</td>
<td>5.97</td>
<td>1-7</td>
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<td>2</td>
<td>How likely is this treatment to make permanent improvements in your child’s behavior?</td>
<td>5.03</td>
<td>1-7</td>
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<td>3</td>
<td>How costly will it be to carry out this treatment?*</td>
<td>2.90</td>
<td>1-7</td>
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<td>4</td>
<td>How willing are you to carry out this treatment?</td>
<td>6.41</td>
<td>1-7</td>
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<td>5</td>
<td>How much time will be needed each day for you to carry out this treatment?*</td>
<td>4.83</td>
<td>1-7</td>
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<tr>
<td>6</td>
<td>How confident are you that the treatment will be effective?</td>
<td>4.93</td>
<td>1-7</td>
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<tr>
<td>7</td>
<td>How willing would you be to change your family routine to carry out this treatment?</td>
<td>6.66</td>
<td>5-7</td>
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<tr>
<td>8</td>
<td>How disruptive will it be to your family (in general) to carry out this treatment?*</td>
<td>2.59</td>
<td>1-5</td>
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<tr>
<td>9</td>
<td>How effective is this treatment likely to be for your child?</td>
<td>5.03</td>
<td>2-7</td>
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<tr>
<td>10</td>
<td>How well will carrying out this treatment fit into the family routine?</td>
<td>5.24</td>
<td>1-7</td>
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</tbody>
</table>

*Note. All items scored 1 (not at all) to 7 (very likely), * = item was reversed scored for acceptability total.*
CPAE
Behavioral Assessment and Treatment

Biological vs. Behavioral variables?

“Can my child control their own behavior?”
Behavioral Assessment

• Baseline assessment
  • *Structural* – daily routine, predictability, rules, requirements
  • *Functional* – consequences for appropriate & inappropriate behavior

• Information gathered from parents, teachers, and other healthcare providers (data sheets, permanent product, technology, etc.)
Family Accommodation and Secondary Gains

• **Family accommodation** = Family involvement in routines that exacerbate and maintain severe problem behavior, anxiety, OCD, etc.

• Changes in behavior can be related to biology alone, but research indicates that sometimes as children persist in challenging behavior, parental behavior also changes especially when a child is ill (and parents are burdened over time).
Systemic Cycle

1. Child Anxiety and Distress (low parental tolerance)
2. Family Accommodation
3. Short-Term Reduction in Distress
4. Continued Dependence on Parents for Regulation
5. Maintenance of Symptoms
Family Accommodation and Secondary Gains

- **Parents may:**
  - Provide repeated reassurance
  - Allow the child to sleep in parent’s bed
  - Facilitate general avoidance and avoidance of social and school engagements
  - Provide items to mitigate anxiety
  - Doing things which fall under the child’s responsibility
  - Prepare special meals
Negative Impact of Family Accommodation

- Promotes avoidance
- Reduces self-regulation
- Reduces insight
- Reduces motivation for treatment

THIRTY YEARS OF RESEARCH ON THE FUNCTIONAL ANALYSIS OF PROBLEM BEHAVIOR

GRACIE A. BEAVERS AND BRIAN A. IWATA
UNIVERSITY OF FLORIDA

AND

DOROTHEA C. LERMAN
UNIVERSITY OF HOUSTON–CLEAR LAKE

Hanley, Iwata, and McCord (2003) reviewed studies published through 2000 on the functional analysis (FA) of problem behavior. We update that review for 2001 through 2012, including 158 more recent studies that reported data from 445 FAs. Combined with data obtained from Hanley et al., 435 FA studies, with line graphs for 981 FAs, have been published since 1961. We comment on recent trends in FA research and introduce the studies in the 2013 special issue of the Journal of Applied Behavior Analysis.

Key words: functional analysis, problem behavior
### Table 5
Summary of Functional Analysis Outcomes

<table>
<thead>
<tr>
<th>Topography</th>
<th>Undiff</th>
<th>Diff</th>
<th>Esc</th>
<th>Attn</th>
<th>Tang</th>
<th>Auto</th>
<th>Mult</th>
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<tbody>
<tr>
<td>Self-injury</td>
<td>9 (22)</td>
<td>60 (282)</td>
<td>18 (83)</td>
<td>4 (63)</td>
<td>6 (34)</td>
<td>21 (76)</td>
<td>11 (26)</td>
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<tr>
<td>Aggression</td>
<td>10 (12)</td>
<td>45 (95)</td>
<td>17 (41)</td>
<td>12 (21)</td>
<td>10 (16)</td>
<td>1 (2)</td>
<td>5 (15)</td>
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<tr>
<td>Property destruction</td>
<td>0 (0)</td>
<td>7 (9)</td>
<td>2 (2)</td>
<td>2 (2)</td>
<td>0 (2)</td>
<td>1 (1)</td>
<td>2 (2)</td>
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<tr>
<td>Pica</td>
<td>0 (0)</td>
<td>5 (11)</td>
<td>0 (0)</td>
<td>0 (1)</td>
<td>0 (0)</td>
<td>5 (8)</td>
<td>0 (2)</td>
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<tr>
<td>Disruption</td>
<td>0 (0)</td>
<td>10 (26)</td>
<td>0 (11)</td>
<td>0 (3)</td>
<td>0 (1)</td>
<td>6 (7)</td>
<td>4 (4)</td>
</tr>
<tr>
<td>Vocalizations</td>
<td>2 (3)</td>
<td>45 (59)</td>
<td>9 (15)</td>
<td>14 (17)</td>
<td>5 (6)</td>
<td>10 (10)</td>
<td>7 (11)</td>
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<tr>
<td>Noncompliance</td>
<td>0 (0)</td>
<td>17 (25)</td>
<td>8 (9)</td>
<td>7 (9)</td>
<td>2 (3)</td>
<td>0 (0)</td>
<td>0 (4)</td>
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<tr>
<td>Elopement</td>
<td>0 (0)</td>
<td>12 (15)</td>
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<td>5 (5)</td>
<td>4 (4)</td>
<td>0 (0)</td>
<td>3 (6)</td>
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<td>Stereotypy</td>
<td>0 (1)</td>
<td>16 (46)</td>
<td>1 (7)</td>
<td>0 (0)</td>
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<td>14 (33)</td>
<td>1 (6)</td>
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<td>Tantrums</td>
<td>0 (0)</td>
<td>2 (8)</td>
<td>1 (3)</td>
<td>0 (1)</td>
<td>1 (2)</td>
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<td>Other</td>
<td>0 (0)</td>
<td>17 (30)</td>
<td>2 (6)</td>
<td>1 (6)</td>
<td>1 (1)</td>
<td>10 (11)</td>
<td>5 (6)</td>
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<tr>
<td>Aberrant</td>
<td>16 (21)</td>
<td>172 (316)</td>
<td>63 (120)</td>
<td>25 (72)</td>
<td>20 (32)</td>
<td>1 (2)</td>
<td>63 (90)</td>
</tr>
<tr>
<td>Total number</td>
<td>37 (59)</td>
<td>408 (322)</td>
<td>121 (397)</td>
<td>70 (200)</td>
<td>49 (101)</td>
<td>69 (150)</td>
<td>99 (174)</td>
</tr>
</tbody>
</table>

**Note.** Undiff = undifferentiated results, Diff = differentiated results, Esc = maintenance by escape, Attn = maintenance by attention, Tang = maintenance by tangible reinforcers, Auto = maintenance by automatic reinforcement, Mult = multiple sources of control.

aNumbers in parentheses indicate current data combined with those from Hanley et al. (2003).

b“Sample” refers to all line graphs presented in included studies.
Why does problem behavior occur?

Behavior

Gain

- Attention
- Preferred Activities, toys, food, etc.
- Stimulation

Escape

- Attention
- Nonpreferred Activities
- Stimulation
Parents with children who are ill, often let parenting contingencies relax (i.e., *accommodate*)... 

<table>
<thead>
<tr>
<th>Function</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Escape function</strong></td>
<td>(oppositional/defiance)</td>
</tr>
<tr>
<td>• No longer require child to complete tasks/demands</td>
<td></td>
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<tr>
<td><strong>Attention function</strong></td>
<td>(separation anxiety/demanding)</td>
</tr>
<tr>
<td>• Provide more attention to child than usual due to illness, appointments, home from school, etc.</td>
<td></td>
</tr>
<tr>
<td><strong>Tangible function</strong></td>
<td>(refusal to transition off items, accept “no,” etc.)</td>
</tr>
<tr>
<td>• Allow child to have <em>free and unlimited access</em> to their preferred items (e.g., tablet, phone, video games, television, etc.)</td>
<td></td>
</tr>
</tbody>
</table>
## Function of Behavior – MEDICAL Screening Tool (FOB MED)

**Name:**

**Date:**

**Age:**

**Diagnosis:**

**Challenging Behavior:**

1. **Does your child have difficulty when you pay ATTENTION to something or someone else other than them?**
   (EXAMPLE: parent making a phone call, parent playing with sibling, parent attending to guests at home, etc.)
   **(Intensity: 1—2—3—4—5) (How often: daily #; weekly #; monthly #)**
   Please Circle: YES / NO

2. **Does your child have difficulty when TANGIBLE items or preferred activities are taken away, removed, required to share, restricted, or delayed (required to wait) from him/her?**
   (EXAMPLE: toys, tablet/phone/computer, going outside, etc.)
   **(Intensity: 1—2—3—4—5) (How often: daily #; weekly #; monthly #)**
   Please Circle: YES / NO

3. **Does your child have difficulty when asked them to complete a task or a DEMAND is asked of them?**
   (EXAMPLE: chores, homework, bed time, get dressed, bath time, etc.)
   **(Intensity: 1—2—3—4—5) (How often: daily #; weekly #; monthly #)**
   Please Circle: YES / NO

4. **Does your child have difficulty (challenging behavior) when he/she is ALONE (when no one else is around)?**
   (EXAMPLE: playing in their room, etc.)
   **(Intensity: 1—2—3—4—5) (How often: daily #; weekly #; monthly #)**
   Please Circle: YES / NO

**Intensity:**

- **1 = mild** - challenging behavior – but can manage current behavior
- **2 = moderate** - challenging for caregivers – requires effort to manage behavior
- **3 = severe** - causing tissue damage to self or hurting others – cannot manage behavior

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1. **(a) After you see challenging behavior, do you typically: tell your child to stop (reprimand), try to soothe your child, discuss the behavior, or explain to them why they shouldn’t do it?**
   **Other:**
   Please Circle: YES / NO

2. **(a) After you see challenging behavior, is the item ever given back or is your child allowed to participate in the activity (e.g. toy, food, tablet, phone, computer time, go outside, or fun activity)?**
   Please Circle: YES / NO

3. **(a) After you see challenging behavior, does your child typically (Circle all that apply): leave the area or task, argue with you, go to a calming place, go to timeout, not complete what you asked them to do, go somewhere to be alone, or go play with toys and other preferred items, complete task ONLY if you help?**
   **Other:**
   Please Circle: YES / NO
### Function of Behavior - MEDICAL Screening Tool (FOR-MED-TEEN)

<table>
<thead>
<tr>
<th>Name:</th>
<th>Date:</th>
<th>Age:</th>
<th>Diagnosis:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

#### Challenging Behavior:

1. Do you get to spend enough time with (ATTENTION) your mother or father (or care provider) during the week? Would you like to spend more time with your mother or father? (How often: daily #; weekly #; monthly #)  
   1. (a) How do you typically get their attention?  
2. (b) What types of things do you wish you could do more of with your mother?  
   Father:  
   (Q of A: physical contact, close proximity, vocal enthusiasm, interests, how often)  
   Is it hard for you to stop using your favorite items (e.g., Legos or electronics) or stop a favorite activity (TANGIBLE)? What about when these things are taken away from you, have you to share, or you have to wait for these things?  
   (EXAMPLE: toys, talk/time/computer, going outside, etc.)  
   (*Difficulty: 1—2—3—4—5) (Access: daily #; weekly #; monthly #)  
   2. (a) If you could choose, how long would you use your favorite items and engage in your favorite activities during the day?  
   3. (b) What are the rules in your home about access to your preferred activities?  
3. Do you find it difficult to do your homework, clean your room, complete chores (or follow directions) when your parents ask (ESCAPE/DEMAND)?  
   (EXAMPLE: chores, homework, bed time routine, get dressed, etc.)  
   (*Difficulty: 1—2—3—4—5) (How often: daily #; weekly #; monthly #)  
3. (a). After you are asked to do something at home, do you typically (Circle all that apply): say yes - finish it as quick as possible, try to leave the area or task, argue with your parents, go somewhere else, get upset, continue playing with your favorite things or activities, or complete tasks only if your parents help you?  
   Other:  
4. Do you find yourself doing the challenging behavior (e.g., repetitive behavior, skin picking, etc.) when you are ALONE (when no one else is around)? (e.g., in your room, bathroom, etc.) (How often: daily #; weekly #; monthly #)  
   3. (a). Do you care if someone else sees you engaging in the behavior?  
   4. (b). How difficult is it for you to hold yourself back from the behavior?  
   (*Difficulty: 1—2—3—4—5)  

#### Difficulty scale:  
1 = mildly difficult - challenging - but can manage current behavior daily  
3 = moderately difficult - challenging - requires continual effort to manage behavior  
6 = very difficult - causes Challenging behavior - cannot manage behavior
Treatment Recommendations Based on Behavior and Function

Empirically Supported Strategies
Behavioral Definitions

- Obsessions
  - Compulsions

- Tics
  - Vocal tics
  - Motor tics

- Stereotypy

- High-preferred activity

Positive reinforcement

Automatic reinforcement

Negative reinforcement

Negative reinforcement
Individualizing Treatment – Family Support and Therapy

• Minimizing “family accommodation” to OCD and other behaviors.
• In turn, decreasing “secondary gains”
• Dynamic changes in Parenting Structure and Styles with fluctuation in symptoms:
  • Acute phases (“flares” or “Flare-ups”)
  • Absence of infection (“back to normal?”)
Example of Function-based Treatment

Attention Maintained Behavior

- Promote functional communication (FCT)
- Planned Ignoring
- Tolerating a delay or “wait time” for care giver attention
- Tolerating “No” or “Not right now” when care giver attention is NOT available
- Plan predictable “special times” for individual High-Quality Attention
Treatment Triage Recommendations and Collaborations

- **Mild OCD symptoms:**
  - Cognitive Behavior Therapy (CBT) with Exposure and Response Prevention (ERP) focus

- **Moderate to Severe OCD symptoms:**
  - ERP (Exposure and Response Prevention)
  - Habit Reversal Training (HRT or CBIT) for tics, hair pulling, skin picking, etc.
  - ERP or HRT in combination with Acceptance and Commitment Therapy (ACT)

- **Other Psychiatric Concerns:**
  - ARFID – Feeding therapies/clinics
  - Psychiatry/Neuropsychiatry/Sleep, etc.
Parent Management Training (PMT)

- Encouraging families to not participate in behaviors accommodating the child’s avoidance and rituals
- Positively reinforcing desired behaviors
- Setting clear limits, expectations, and consequences
- Establishing reward systems
- Particularly useful when PANS patients are not ready or willing to use CBT themselves (Lebowitz et al. 2014).
Parent Management Training (PMT)
Alan E. Kazdin (2005)

*Parent Management Training: Treatment for Oppositional, Aggressive and Antisocial Behavior in Children and Adolescents*

Also see: Kazdin, Siegel, & Bass (1992). Problem-Solving Skills Training plus Parent Management Training
• Rita – 8 yo female
• Acute onset: 10/4/2018 (positive strep) – symptoms decreased with Motrin

• **Behaviors of Concern:**
  • Disruptive behavior (crying, complaining),
  • Somatic complaints (throat/belly),
  • Tics/rituals (inhaling harshly/rubbing hands), hyperactivity (dancing/constant moving/episodes),
  • Separation anxiety (wants parents next to her constantly),
  • OCD/Fears (constant needing to talk about obsessions - spiders/snakes/bugs – worse with “flares”).
• Medical Assessment: 1A (Other Encephalopathy)
  • *Treatment*: Naproxen (Start Tiered Treatment)

• Behavioral Assessment: FOB-MED results: identified a hypothesized *Attention and Tangible* functions, especially with Mother
  • *Treatment*: Behavioral Strategies tailored to Family Accommodation (*Attention/Tangible*) and Parent Management Training (PMT)
CPAE Clinic Summary Data
Behavioral Clinical Procedures: Initial Assessment

1. Review records, interview, observation, team collaboration
2. FOB-MED tool used to determine Ho: function of behavior.
3. Provide parents/caregivers with empirically supported practices and resources (e.g., Tx linked to function, PMT, ERP/ACT, HRT/CBIT, etc.)
4. TARF-R measures treatment acceptability.
# SCATTERPLOT

Fill in each square that represents when the behavior occurred:

Month: **February/March**  Year: **2021**  Name: **AA**

<table>
<thead>
<tr>
<th>Mild Behavior</th>
<th>Moderate Behavior</th>
<th>Severe Behavior</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poufing, non-compliance, talking back</td>
<td>Yelling, screaming, stomping feet, slamming belongings, kicking feet, tantrum</td>
<td>Hitting, pushing, grabbing, kicking, property destruction</td>
</tr>
</tbody>
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**Notes:**

- **Feb 1-5:** Generally terrible behavior (has been really bad since he came off Axlove) – defiant, angry, brutally mean to his siblings/parents – especially difficult in any transition and at night.
- **Feb 6:** Started Naproxen – continued terrible behavior.
- **Feb 7:** Had to stay home from family get together because of his terrible violence and throwing in the garage.
- **Feb 8:** Hard time getting up for school but pretty good today willingly went to Boy Scouts.
- **Feb 9:** Andrew was angry that his electronics had been taken away for a while, he stole my car keys and got his electronics out of the car where he saw I had hidden them.
Feb 10 Great behavior!
Feb 11 Mostly great but we were late to sister's dance class and that made him on edge
Feb 12 Purposely annoying to siblings
Feb 13 Good but annoying siblings and getting in their space
Feb 14 Angry for several hours after I wouldn't let him have chips at Subway
Feb 15 Great behavior!
Feb 16 Pretty good but annoying to siblings
Feb 17 Great behavior said he is starting to count syllables again
Feb 18 A couple minor issues but good *Started 5 day course of Enfamilomycin upon suggested of primary care doctor
Feb 19 Great!
Feb 20 Was very mean to sister, was mad at brother for telling on him, shoved mother and threw Alexa music device (we let him have gluten today and could be a cause)
Feb 21 Good behavior
Feb 22 Brother bothered Andrew while he was waking up and Andrew slapped Ryan causing lots of bleeding on eyebrow - he didn't mean to but another example of no body control
Feb 23 Can't seem to stop bothering his sister
Feb 24 Feisty hyper at bedtime - hard time regulating himself but still compliant!
Feb 25 Great behavior - a little hyper at bedtime
Feb 26 Fantastic behavior - his sister spit on him for some reason and he remained very calm - previously that would have started WWIII
Feb 27 Had a tough morning, insulted brother and freaked out about his gluten free bagel not being toasted enough - often had food related complaints - food is a hot button for him - we did give him gluten the day before at a family get together and we hypothesize that any gluten contributes to his inflammation causing behavior issues, but he has been primarily gluten free for a year so this is only one factor
Feb 28 Had time going to sleep but pretty good day - minor argument with cousin about playing Fortnite
March 1 Attended first baseball practice and regular Boy Scout meeting. Went to sleep quickly at night and had a great day.
March 2 Did one hour of homework with Andrew without argument and got it done quickly. Normally this would result in yelling and desistance but it was wonderful!
March 3 Andrew has really transformed - he cares about school, we have had some great conversations, he is happy! Still complains of eyes - mostly when he eats.
March 4 complaining that is syllable counting is getting worse (OCD like behavior) - we are working on Andrew being able to stay home by himself for short periods of time - he has a great deal of anxiety about this - says he thinks we won't come back - I was successful in leaving him home to check the mail while talking to him on the phone.
March 5 Great behavior! Andrew is almost a completely different kid right now!

Andrew has a hard time getting to sleep in general, he is now back to smiling and cracking jokes like he used to, he still has a tough time regulating but so much better than before.
2017
High dose IVIG
IVIG stopped in January

March 20, 2018
Neuroimaging EEG

March 26, 2018
MRI shows persistent 9mm cerebellar lesion

January 2018
Testing in CPAE Clinic (Tucson, AZ)

2018

April 19, 2018
Given Augmentin (antibiotic)

May 24, 2018
Given Famciclovir (antiviral)
Diagnosed with Hypogammaglobulinemia

June 2018
Started IVIG replacement dose.
Given four doses from June to September

September 12, 2018
No improvement with replacement dose.
Request High dose IVIG.

Given Famciclovir (antiviral)

September 23, 2018
Brief Functional Analysis conducted

October 9, 2018
High dose IVIG

December 13, 2018
High dose IVIG

February 8, 2018
High dose IVIG

October 1, 2018
Functional Communication Training started in home with care providers

January 14, 2019
Exposure to illness
Flare – increase in disruptive behaviors
Summary of 40 Cases
Treatment Acceptability summary

Treatment Acceptability Rating Form-Revised
(Reimers et al. 1992)

Acceptability Data ($n = 29$)

$M = 52.97; SD = 9.66; $ Range 31-67

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<th>Item</th>
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<td>How acceptable do you find the treatment to be regarding your concerns</td>
<td>5.97</td>
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<td>How likely is this treatment to make permanent improvements in your</td>
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<td>How costly will it be to carry out this treatment?*</td>
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<td>4</td>
<td>How willing are you to carry out this treatment?</td>
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<td>How much time will be needed each day for you to carry out this treatment?*</td>
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<td>How confident are you that the treatment will be effective?</td>
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<td>How willing would you be to change your family routine to carry out this</td>
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<td>8</td>
<td>How disruptive will it be to your family (in general) to carry out this</td>
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<td>9</td>
<td>How effective is this treatment likely to be for your child?</td>
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<td>How well will carrying out this treatment fit into the family routine?</td>
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Note. All items scored 1 (not at all) to 7 (very likely), * = item was reversed scored for acceptability total
• **Bio-Behavioral Investigations:**

• **Behavioral Treatment and Therapy**
  • Combinations of Bio and Behavioral Treatments?
  • Dosage? Timing?
  • Control/monitor behavioral therapies along with biological interventions
  • RCT

• **Pediatric Neuroimaging**
  • Accurate imagining using training protocols for CPAE children


• **Long-term Treatment Variables**
  • How do behavioral treatments and PMT hold up across “Flares” (i.e., exposure to subsequent infection/challenges to structure and consistency – regression and resurgence)
Thank you
References and Resources:

References and Resources (page 2):