

APPLICATIONS OF ABA IN PEDIATRIC MEDICAL REHABILITATION SETTINGS

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CHILDREN WITH CHRONIC COMPLEX MEDICAL CONDITIONS

Increasing population:

- Improved prenatal medicine – more medically complex children are born
- Better neonatal and pediatric care – individuals are living longer

In many ways this is a new population

CHILDREN WITH CHRONIC COMPLEX MEDICAL CONDITIONS

Who are these children?

Children with...

- Cancer/Tumor
- Pre or post transplant/Organ failure
- Genetic/Chromosomal abnormalities
- Acquired or traumatic brain injuries
 - Encephalitis
 - Strokes
 - Motor Vehicle Accident

CHILDREN WITH CHRONIC COMPLEX MEDICAL CONDITIONS

Who are these children?

Children with...

- Movement disorder (paralysis/palsy, MS, spasticity)
- Respiratory issues (tracheostomy, BiPAP/CPAP, or Ventilator support)
- Feeding/GI issues
- Sickle Cell
- Cystic Fibrosis (CF)
- Diabetes
- Intractable seizures
- Chronic Pain
- Multi-system medical anomalies

CHILDREN WITH CHRONIC COMPLEX MEDICAL CONDITIONS

What is your experience with this population?

CHILDREN WITH CHRONIC COMPLEX MEDICAL CONDITIONS

Who are these children?

- Children that require ongoing medical care, often from multiple medical specialties
- Frequent hospitalizations
- Complicated medical regimens and medication schedules

CHILDREN WITH CHRONIC COMPLEX MEDICAL CONDITIONS

There is no biological vacuum

- Many children have a number of physiological anomalies in addition to cognitive impairments

CHILDREN WITH CHRONIC COMPLEX MEDICAL CONDITIONS

These children are exposed to numerous hospitalizations and endure many painful and invasive medical procedures from birth.

Mechanical restraints (i.e., welcome sleeves) and chemical restraints (i.e., sedatives and anesthesia) are used frequently.

CHILDREN WITH CHRONIC COMPLEX MEDICAL CONDITIONS

Medical trauma

Over generalized physiological arousal (classical conditioning)

Systematic and accidental reinforcement of aggressive and disruptive behaviors (operant conditioning)

MEDICAL REHABILITATION SETTINGS

Franciscan Children's: Medical Rehabilitation

Kennedy Krieger Institute: Pediatric Rehabilitation Unit

MEDICAL REHABILITATION SETTINGS

Franciscan Children's: Medical Rehabilitation

42 beds across two medical units

The largest dedicated pediatric rehabilitation center in New England

Service children as young as a couple months into early adulthood

Length of stay varies from 1 to 2 weeks up to 5 to 6 years

PSYCHOLOGY'S ROLE

Neuropsychological Testing (snap shot assessment)

Neurological Monitoring (progress monitoring)

Adjustment to medical condition/hospital stay

Coping with loss and end of life planning

Discharge preparation

PSYCHOLOGY'S ROLE

Preparation for medical procedures

Reducing problem behaviors

- Medical refusal
- Removal of medical equipment
- Self-stimulatory behaviors related to medical equipment
- Reducing impulsive behaviors

Increasing motivation and compliance with therapies

Monitoring behavioral problems

Evaluating preferences and responses to stimuli

Writing behavior plans

Teaching independence of medical care

Assisting in an individual's relearning of activities of daily living

Parent and staff training

CASE STUDY 1: TOM

6 year old male

Has lived on the rehab unit for 5 years

Was born with lung disease and heart failure

Needs a heart and lung transplant

Was not expected to survive past 1 year

CASE STUDY 1: TOM

Requires 24 hour ventilator support

Improving medical stability

Non-ambulating

Non-verbal (signs “more” & “all done” and will point to the TV)

Significant cognitive impairment

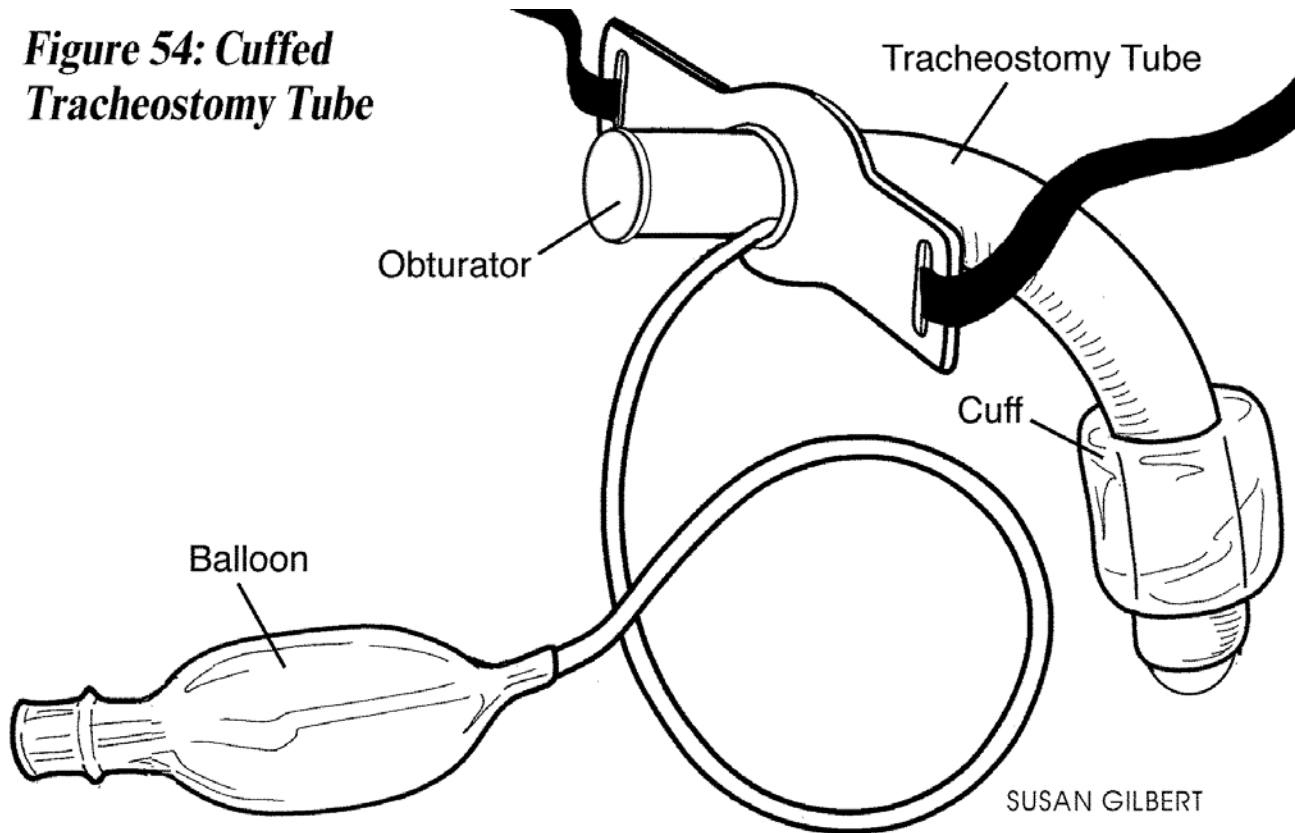
CASE STUDY 1: TOM

Consult concern: Destroys trach and pulls trach off (self-decannulation)

Risk: could cause death

CASE STUDY 1: TOM

Figure 54: Cuffed Tracheostomy Tube



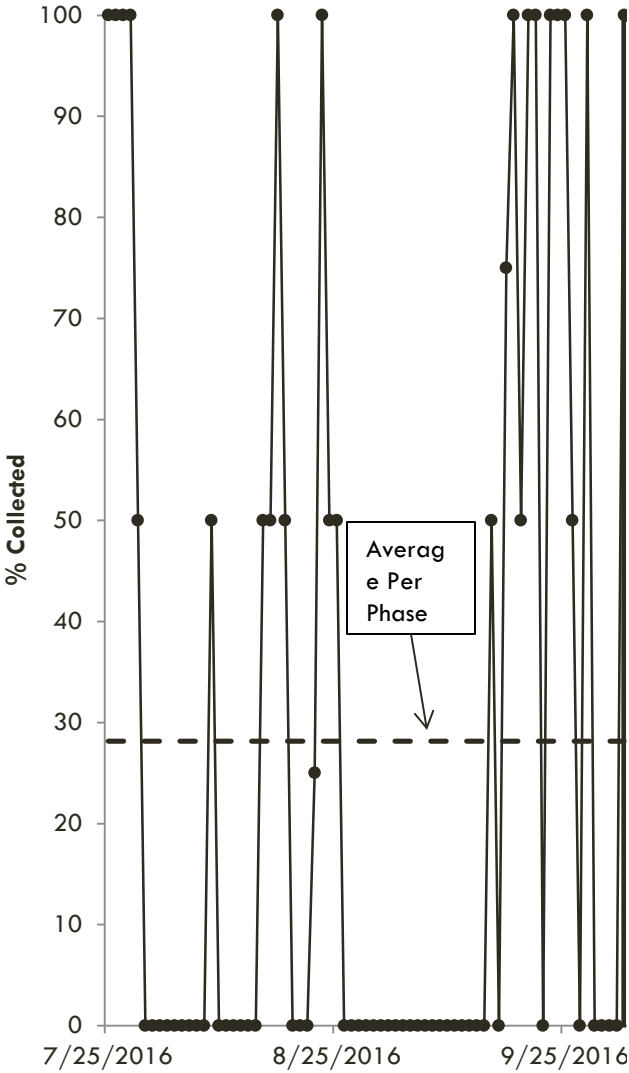
CASE STUDY 1: TOM

Step 1

- Collect data

Percent of Behavioral Data Collected by Nurses

A: Standard Written Instruction

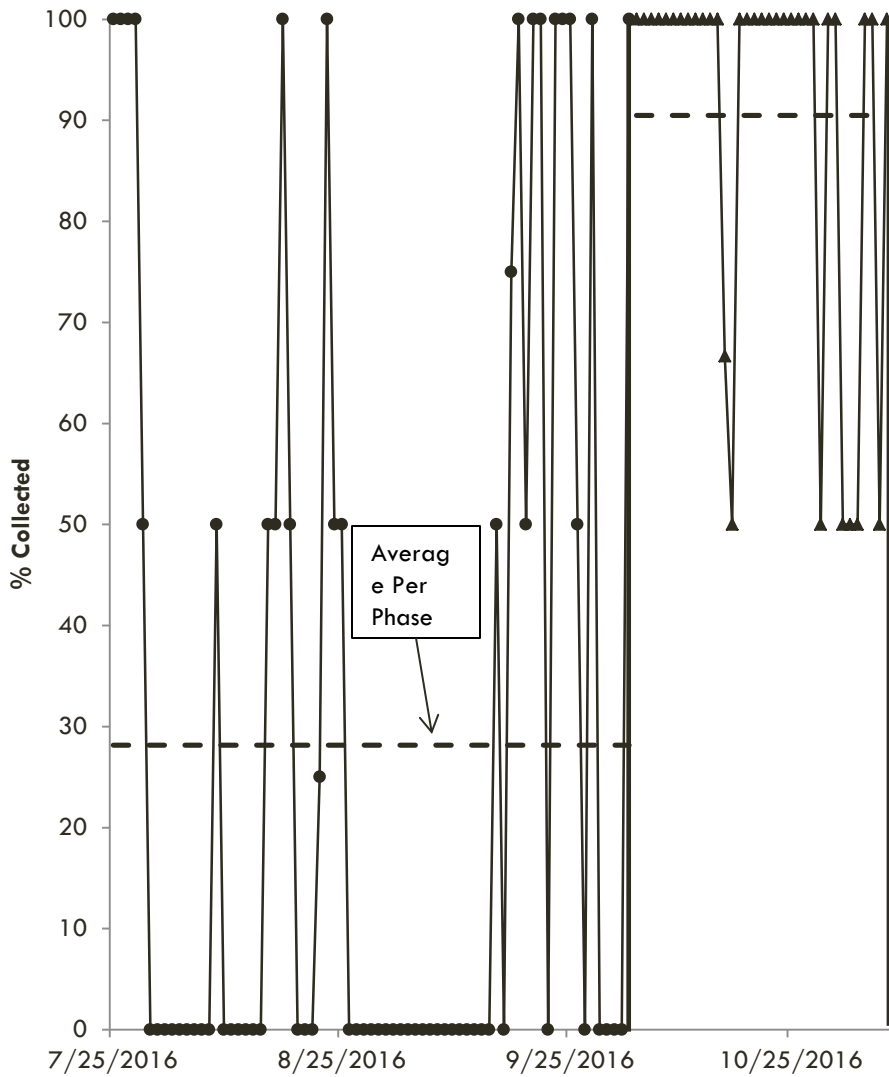


Date

Percent of Behavioral Data Collected by Nurses

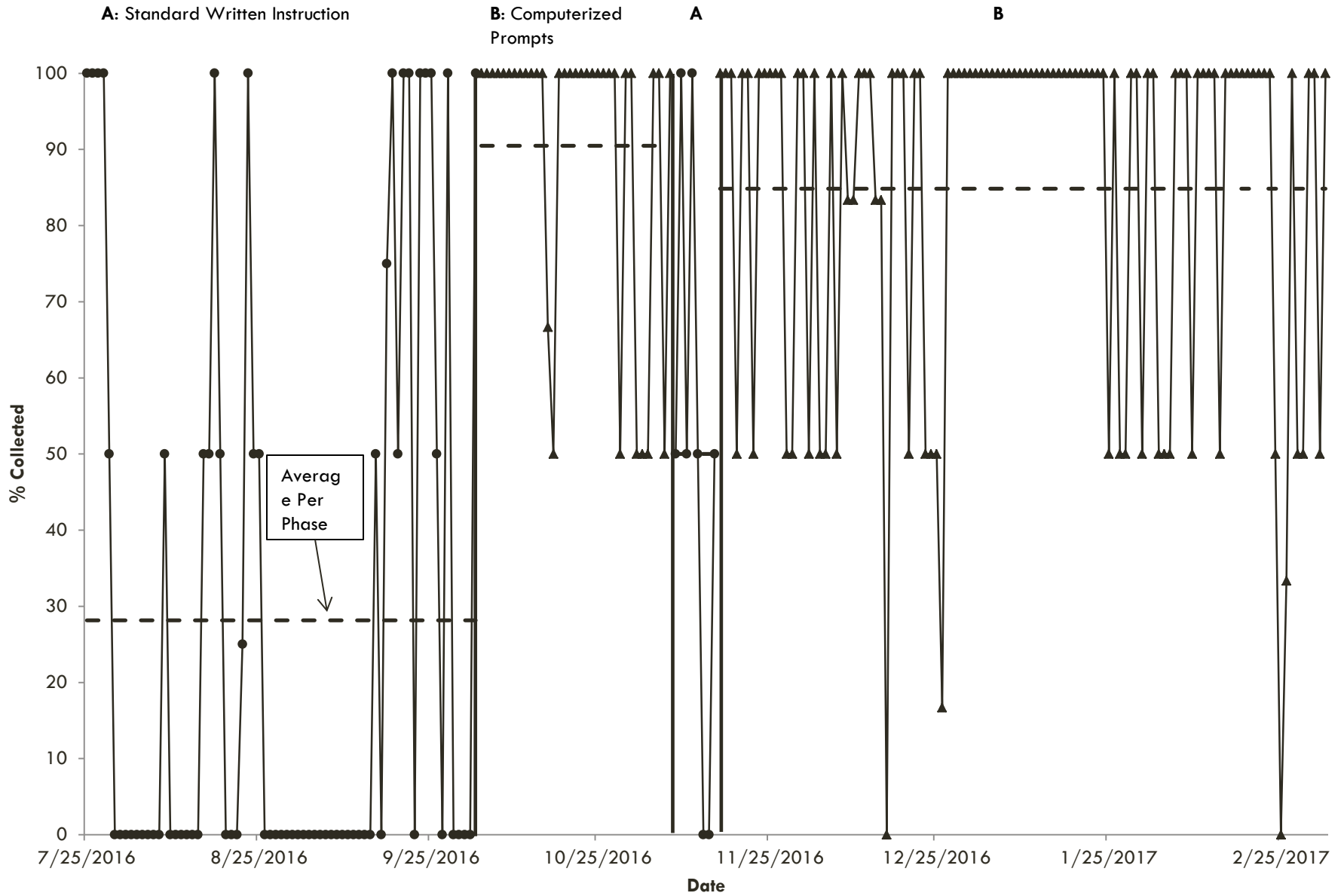
A: Standard Written Instruction

B: Computerized Prompts



Date

Percent of Behavioral Data Collected by Nurses



CASE STUDY 1: TOM

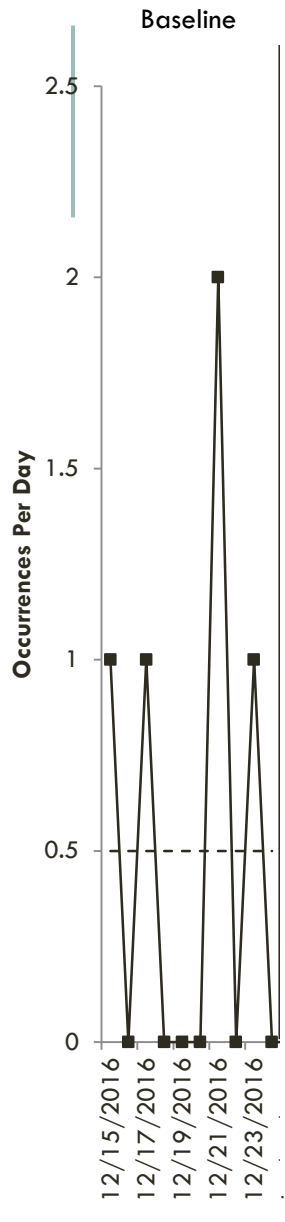
Step 2

- Determine function
 - Access to attention
 - Access to water
 - Self-stimulatory

Step 3

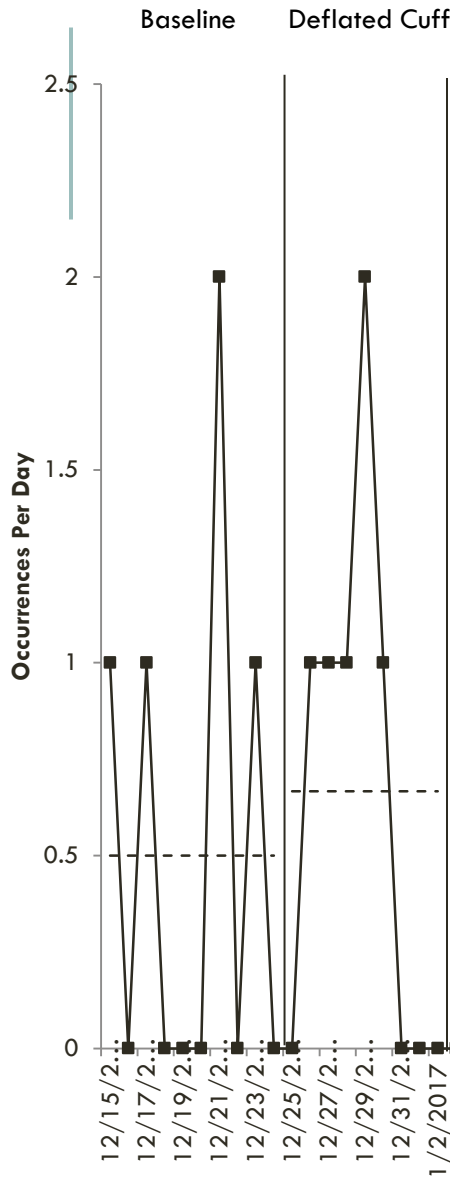
- Evaluate Interventions
 - Reduce attention (low treatment adherence – ineffective)
 - Reinforce safe behavior (low treatment adherence – ineffective)
 - Aversive flavor (increased behavior)
 - Sensory Extinction
 - Abolishing operations

Daily Frequency of New Trachs Required

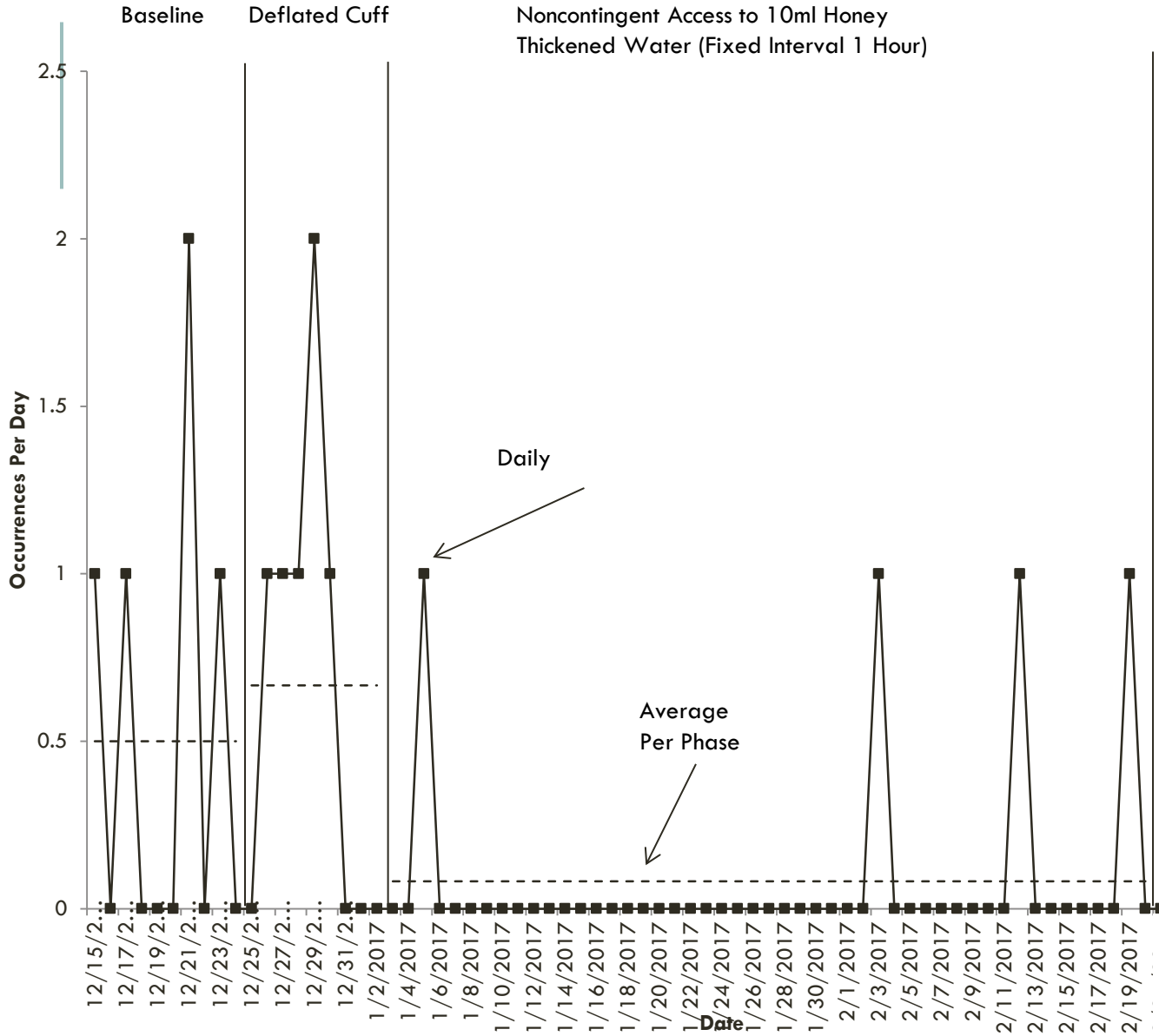


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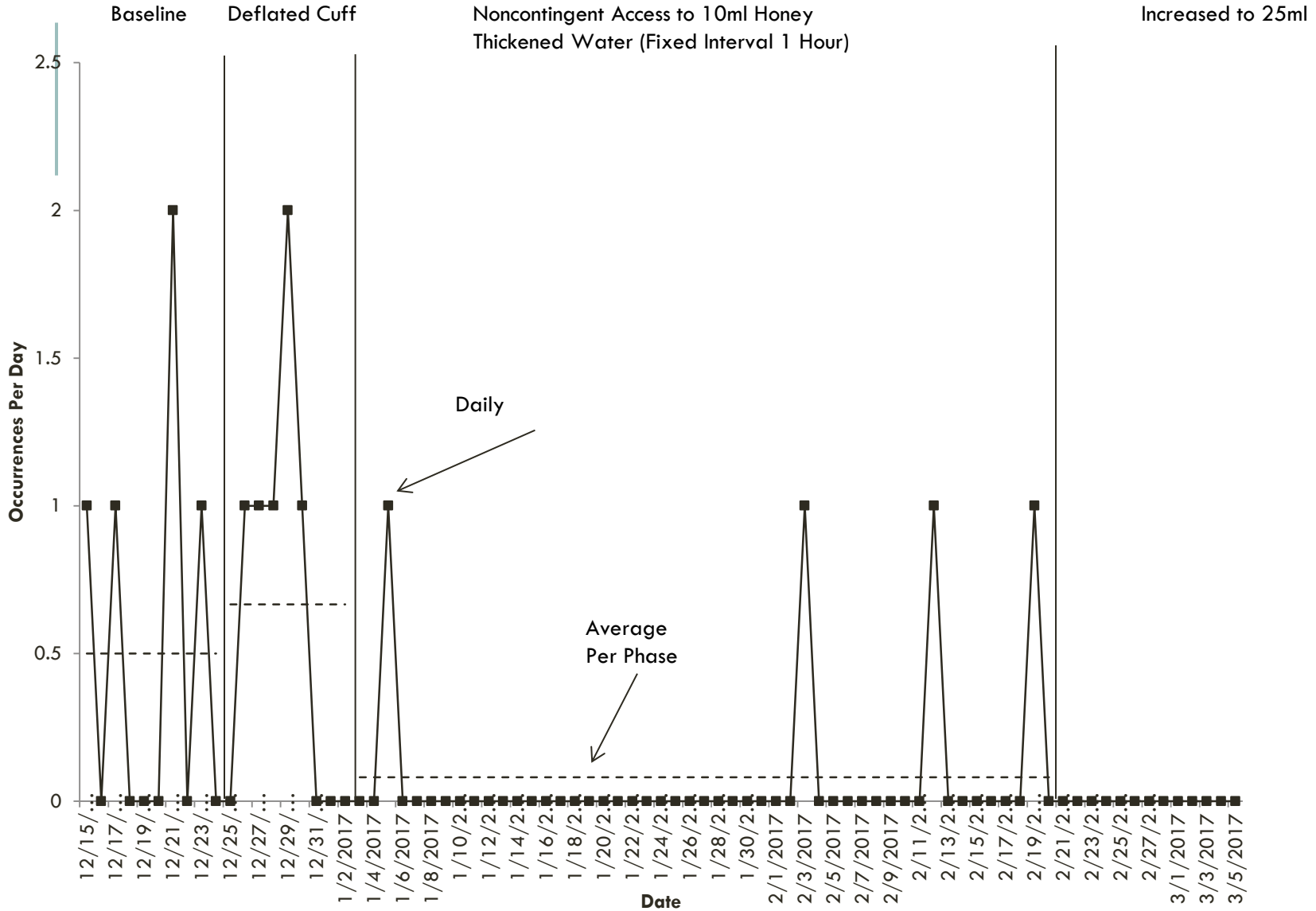
Daily Frequency of New Trachs Required



Daily Frequency of New Trachs Required



Daily Frequency of New Trachs Required



CASE STUDY 2: MAX

5 year old male

Rare genetic deletion – resulting in extremely low tone.

Severe obstructive sleep apnea (OSA) and recurrent aspiration pneumonia (9 hospitalization in the past year)

Diagnosed with autism - Highly verbal and impulsive

CASE STUDY 2: MAX

Reason for admission: CPAP desensitization

CPAP is an effective treatment in 86% of children with OSA

Poor compliance and adherence occurred in 92% of the cases with poor outcomes (Marcus, Davidson-Ward, Mallory, 1995)

Strategies based on the principles of Applied Behavior Analysis have been shown to be the most effective intervention (Koontz, Slifer, Cataldo, Marcus, 2003)

CASE STUDY 2: MAX

Treatment package components:

- Positive & Negative Reinforcement
- Graduated Exposure
- Response Prevention (Escape Extinction)
- Distraction
- Counter Conditioning
- Stimulus Fading
- Demand Fading (Thinning the schedule of reinforcement)
- Systematic Generalization

CASE STUDY 2: MAX



CASE STUDY 2: MAX

Step 1:

- Conduct sleep assessment
- Improve sleep hygiene
- Decrease sleep onset latency
- Decrease nighttime awakening

Step 2:

- Baseline tolerance of mask
 - Trial one: 3 seconds on hand
 - Trial two and three: refusal to allow the mask to touch him

CASE STUDY 2: MAX

Step 3:

- Gain basic compliance (High P)
- Establish SR⁺ contingency (pretending to be racecars and running laps around play room)

Step 4:

- High P (compliance task) → Low P (mask on hand for 1 second) sequence with SR⁺ (more running)

CASE STUDY 2: MAX

Step 5:

- Demand fading (increase duration of mask on hand)

Step 6:

- Move mask: hand → forearm → elbow → shoulder → ear → cheek → nose/face

Step 7:

- Increase duration to 30 second

CASE STUDY 2: MAX

Step 8:

- Stimulus fading (adding each component of the CPAP)

Step 9:

- Shift away from running and generalize to bed

Step 10:

- Use overnight, FC for breaks, escape extinction

CASE STUDY 2: MAX

Notes:

- I ran miles
- Caregivers needed support during first extinction
- Consultation with medical (Pulmonary) team is essential
- Do not fade air pressure levels
- Do not connect the mask to the machine without the machine on
- Do not put a mask on a sleeping child
- By day 7 he was requesting the mask so that he could earn things
- Within a 15 day admission 3 years of battling was over

CASE STUDY 3: BEN

18 year old male with (at baseline):

- Cerebral Palsy (CP)
- Intellectual impairment
- Hearing Impairment
- Non-verbal (understood sign and could make some switch based choice)
- Non-ambulating

CASE STUDY 3: BEN

Ben experienced severe Baclofen withdrawal following a Baclofen pump replacement.

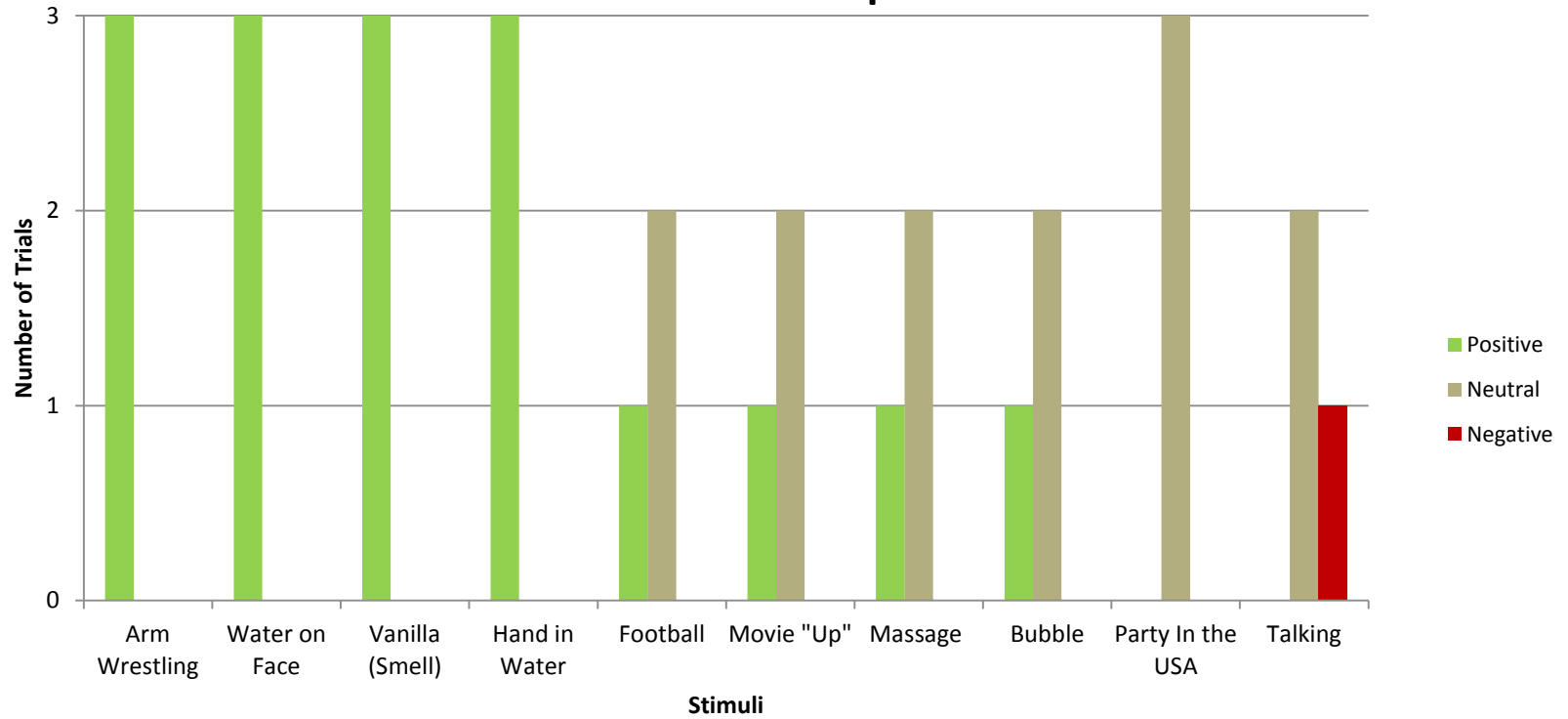
- Resulting in frequent dystonic episode (dystonic storming): spasticity, muscle contraction, sweating, elevated heart rate
- Not associated with a change in consciousness
- Very painful

CASE STUDY 3: BEN

Goals of consult:

- Low responsiveness preference assessment
- Data collection

Preference Assessment Responses



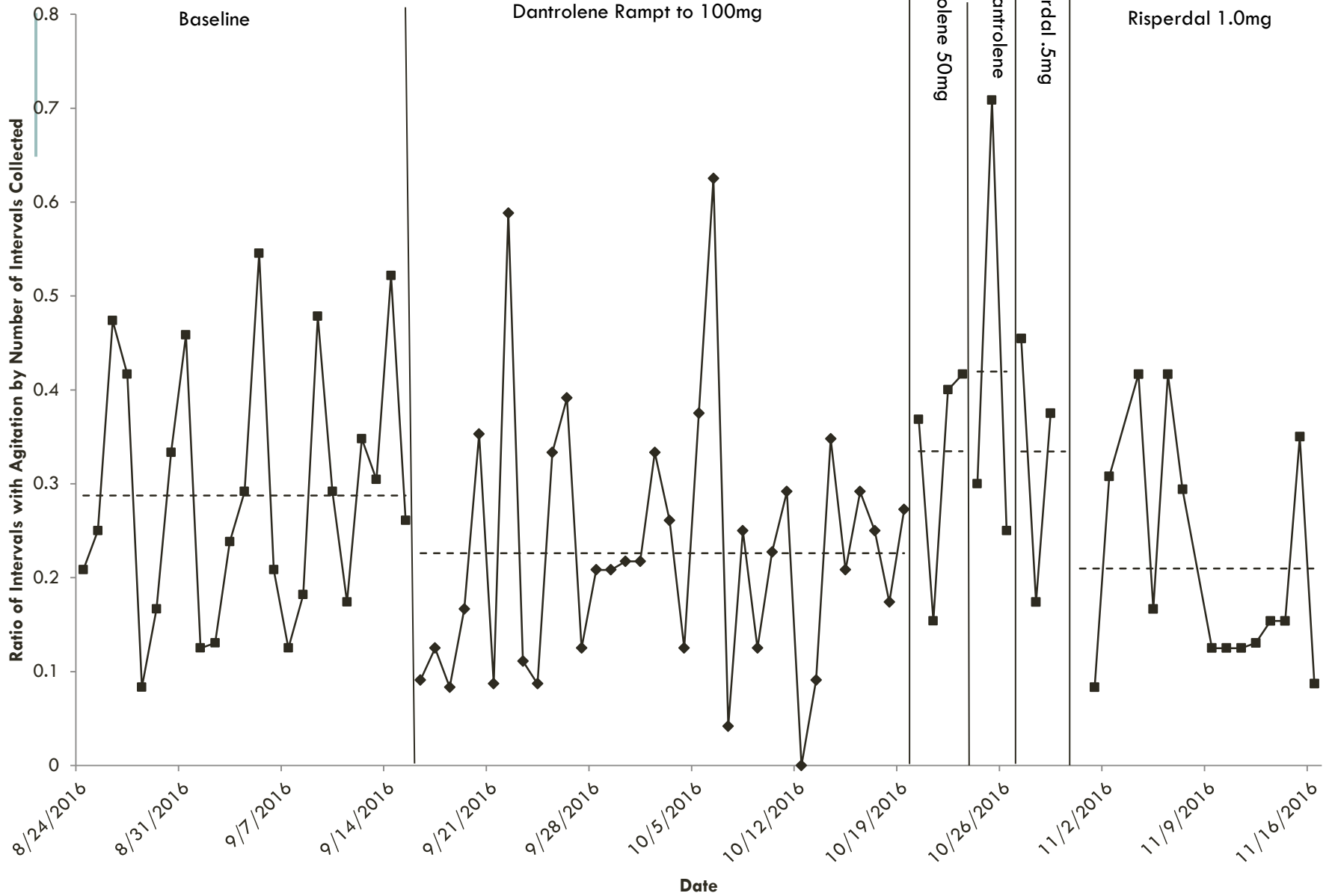
CASE STUDY 3: BEN

- Identified stimuli
 - Arm Wrestling
 - Water on Face
 - Vanilla (Smell)
 - Hand in Water
- Ben's day was imbedded with NCR using these stimuli
- Additionally these stimuli were evaluated as environmental strategies to decrease the length of dystonic episodes.
 - $\frac{3}{4}$ of observed trials, there was a correlation between the use of these strategies and the end of the episode

CASE STUDY 3: BEN

- Data collection
 - Very difficult to judge effect of treatment
 - Variable rates of the behavior
 - Emotionally distressing to watch the behavior
 - 90 min episode and 60 min episode both feel equally as miserable
- *Agitation*: Any combination of two of the following: heart rate above 130, grinding teeth, one of his legs being elevated by his own effort, negative or distressed vocalizations or moaning, significant contractions of arms, significant shaking of body, and/or sweating.
- Momentary time sample once per hour

Agitation



CASE STUDY 4: JEN

- 12 year old girl
- Admission due to a sudden stroke while walking down the stairs at home
- Previous healthy high achieving child
- Home schooled by mom

- Current presentation: Non-verbal, non-ambulating, responsive to environmental stimuli, and seemed to have good receptive language

CASE STUDY 4: JEN

- Reason for consult: Motivation during therapies. Therapy was hard and painful and she would refuse to comply to demands.
- Conducted intake with mom
- Identified horses as her highest preferred topic
- Observed several therapy sessions
- Hypothesized escape was the functions
- Created a horse based token system with brakes from therapy as the backup reinforcer



CASE STUDY 4: JEN

- Conducted a co-treat with PT
- While in the stander, the patient was asked to make specific motor movement
- Patient complied and earned her first token
- Patient wanted to continue to look at the rest of the horse pictures but was prompted back to her work and the pictures were removed
- Patient became upset and started to cry
- Mom got upset and asked me to leave



CASE STUDY 4: JEN

- This case represents the greatest clinical mistake I have ever made (that I know about).
- What did I do wrong?
 - I did not develop a strong enough relationship with the mother or patient
 - I did not consider the emotionality of this case
 - I was too rigid
 - I did not consider/trust the mother's role as her teacher

CONCLUSION

- Research in adult psychotherapy has shown that the strength of the therapeutic relationship is the greatest predictor of positive outcomes
- Better predictor than therapeutic modality
- What matters in life is forming meaningful relationships
- What matters in our work is forming meaningful relationships



QUESTIONS