URINE LUCK: UPPING THE ANTE FOR SUCCESSFUL CATHING IN PEDIATRIC PATIENTS

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OBJECTIVES

- List factors associated with adherence and strategies to promote increased adherence.
- Identify indicators directing need for desensitization to medical procedures versus frank non-adherence.
- Complete analysis of tasks required to complete basic techniques in urological conditions including CIC and sit schedules as basis for desensitization strategies.

HOW WE WILL (HOPEFULLY!) GET THERE

- Adherence
  - What is normal?
  - Predictors
- Research: Adherence Promotion
  - Education v. behavioral
  - Communication
- Putting it all to work
  - Case studies
  - Adherence-promoting elements

CASE 1: AARON

- 2 y.o.: Lumbosacral tumor resected
- 4 y.o.: CIC
- 8 y.o.: referred for nonadherence to CIC
  - Only completed CIC in medical setting
  - At home: delay tactics; tantrums → escape
- Previous strategies
  - Education
  - Topical anesthetics
- Current management: diapers
- Developmental considerations: emerging embarrassment

CASE 2: ELLA

- 9 y.o.: dx of sacral chordoma s/p resection
- Referred to clinic ~ 3 mos post-resection
  - Presenting concern
- Medical anxiety
- Behavioral issues
  - Hypersensitivity
- Past strategies
  - Foley placed under sedation
  - Sit times: pain
    - 3 voids since surgery
- Current strategies
  - Refused CIC → suprapubic tube (SPT) placed
  - SPT exchanges only under sedation
  - Diapers to manage leaks
- Developmental issues

ADHERENCE

RATES OF ADHERENCE

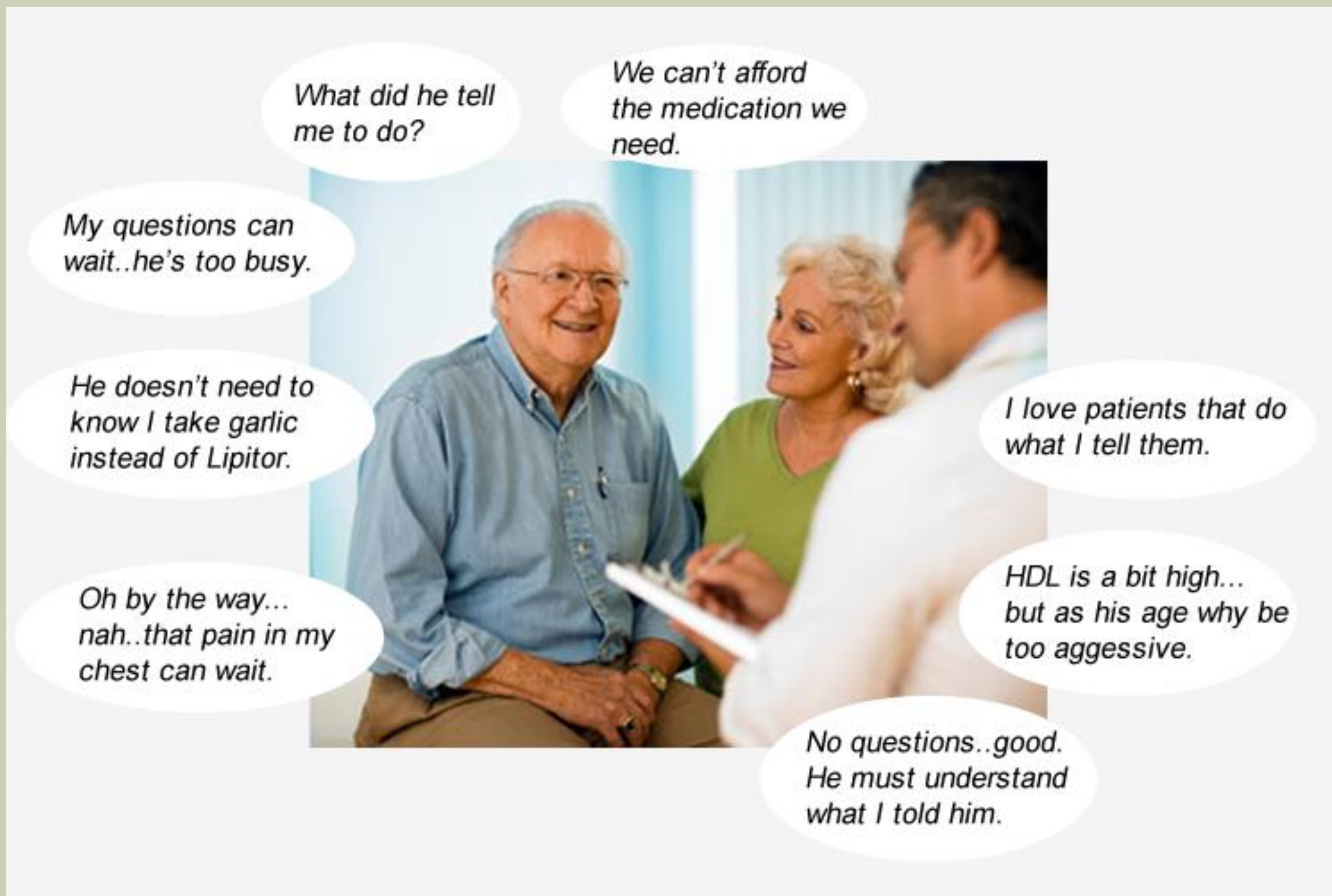
50%

Kahana et al., 2008

NONADHERENCE: ASSOCIATED FACTORS

- Patients/Families
  - Younger age
  - Lower academic attainment
  - Low SES
  - Parental mental health problems
  - Lack of routines
  - Lack of support
- Medical/System
  - Complex recommendations or regimens
  - Mismatch between patient and provider goals
- Individual → Relationship Factors

PROVIDER AND PATIENT COMMUNCIATION



PATIENT AND PROVIDER COMMUNICATION

- Drotar (2009): Review of communication factors in health care
- Associated with:
  - Increased parental satisfaction with care;
  - Increased adherence;
  - Increased communication about psychosocial concerns.
- Described by adolescents as:
  - Familiarity with providers;
  - Longer visits;
  - Protection of confidentiality;
  - Demonstrating interest in teen's interests and whole self—not just condition.
- Difficult communication
  - One study: of top 10 most important issues ranked by patients, only 2 made top 10 in physician ratings

CIC AND COMMUNICATION

- Background: CIC and psychosocial variables
  - Alpert et al (2005): Health related quality of life (HRQOL)
  - Kleiber & McCarthy (1999): Distress during initial CIC procedures
  - Logan et al (2007): Qualitative study of 15 **ADULT** patients requiring CIC
    - "The **communication skills** of nurses helped facilitate the learning experience. In conjunction with nurses' skills, a **friendly relaxed approach** alleviated embarrassment and anxiety, thus **facilitating information exchange and retention of information**."

INTERIM SUMMARY

- Adherence = nonadherence
- Several factors matter
  - Can’t do or won’t do
- Communication is a major factor that impacts others
  - Example: Family routines
- Education about what to do AND how to get it done

CASE REVIEW: PSYCHOSOCIAL AND COMMUNICATION FACTORS

CASE 1: AARON

- At home → delay tactics and eventual tantrums → escape
- Family factors
  - Only child; two parent home
  - No indicators of parental mental health concerns
- Mother directed attempts to CIC
  - Worried about traumatizing child
  - Father's reluctance
- Behavioral factors
  - No behavioral problems outside of CIC

Bottom line: Minimal predictors of poor adherence; anxiety circumscribed to CIC → desensitization

CASE 2: ELLA

- Behavioral observations
- Family factors
  - History of Child Protective Services (CPS) involvement
  - Single parent home; 2 younger siblings
  - Financial stressors
- Behavioral factors
  - Hypersensitivity
  - Anxiety
  - Sleep problems
  - General opposition
- Behavior management strategies

Bottom line: Multiple predictors of poor adherence → likely limited response to desensitization (due to adherence + difficulties with cooperation) → need different tactics and bigger team

ADHERENCE PROMOTION & COMMUNICATION STRATEGIES

RESEARCH

- Education alone (Kahana et al., 2008)
- Discrepancies between provider recommendations and parental report of recommendations (Drotar, 2009)
- "When it comes to promoting behavior change, one of the <provider's> first jobs should be to think of himself or herself as an obstacle remover," ~William Polonsky
- Strategies that help
  - Write it down
  - Addressing the behavior
  - Teach back

WRITE IT DOWN

Patient Instructions signed by Dawn Jeanette Dore-Stites, PHD at 2/21/2014 10:33 AM

Author:	Dawn Jeanette Dore-Stites, PHD	Service:	(none)	Author Type:	Psychologist
Filed:	2/21/2014 10:33 AM	Note Time:	2/21/2014 10:26 AM		

You saw Dr. Hoban (medical) and Dr. Dore-Stites (behavioral) today. You can always reach us at (734) 615-4302.

During today's visit, you expressed concerns about: sleepwalking; aggression during sleep; difficulties falling asleep on his own

There could be several things at play including: sleep apnea; anxiety during day leading to difficult sleep

To assess things further, we are recommending:

1. An overnight sleep study (or PSG) will help us assess medical factors, including breathing, that may affect sleep. An adult will need to stay with through the night.

2. We will get a release of information to talk with your therapist and psychiatrist about how to coordinate our services.

3. Continue to talk with Dr. about the nighttime hallucinations.

Patient Instructions signed by Dawn Jeanette Dore-Stites, PHD at 2/26/2014 5:49 PM

Author:	Dawn Jeanette Dore-Stites, PHD	Service:	(none)	Author Type:	Psychologist
Filed:	2/26/2014 5:49 PM	Note Time:	2/26/2014 5:45 PM		

1. Goal: 4 checks per day. Every day. You are allowed 2 "off days" where you can check as little as 2 times.
2. If you check at least 4 times per day, every day (with exception of 2 off days), you can get out of next appointment (scheduled for 3/12/14 at 5pm).
3. If you do NOT check at least 4 times per day, every day (with exception of 2 off days), you need to attend appointment.

In order to make this happen:

1. NO discussion/threats of [redacted] not being able to attend [redacted] for 2 weeks.
2. [redacted] will contact a friend to see if she/he can text her at 11:00 with "check then shot" as reminder.
3. [redacted] does NOT have to write down numbers.
4. Mom will get phone call on 3/10 as reminder to fax in BG readings. Final determination of whether needs to attend appointment is up to Dawn.

ADDRESSING THE BEHAVIOR

Remember the day you brought me home and you were filled with joy? Go to that place because I just drew all over the walls and shaved the dog.

- Opening question: “How do you think this is going to play out for your kiddo?”
- Main messages
  - Praise the positive—no matter how small
  - Rewards are good (and nontangible is great!)
  - No retreat

TEACH BACK

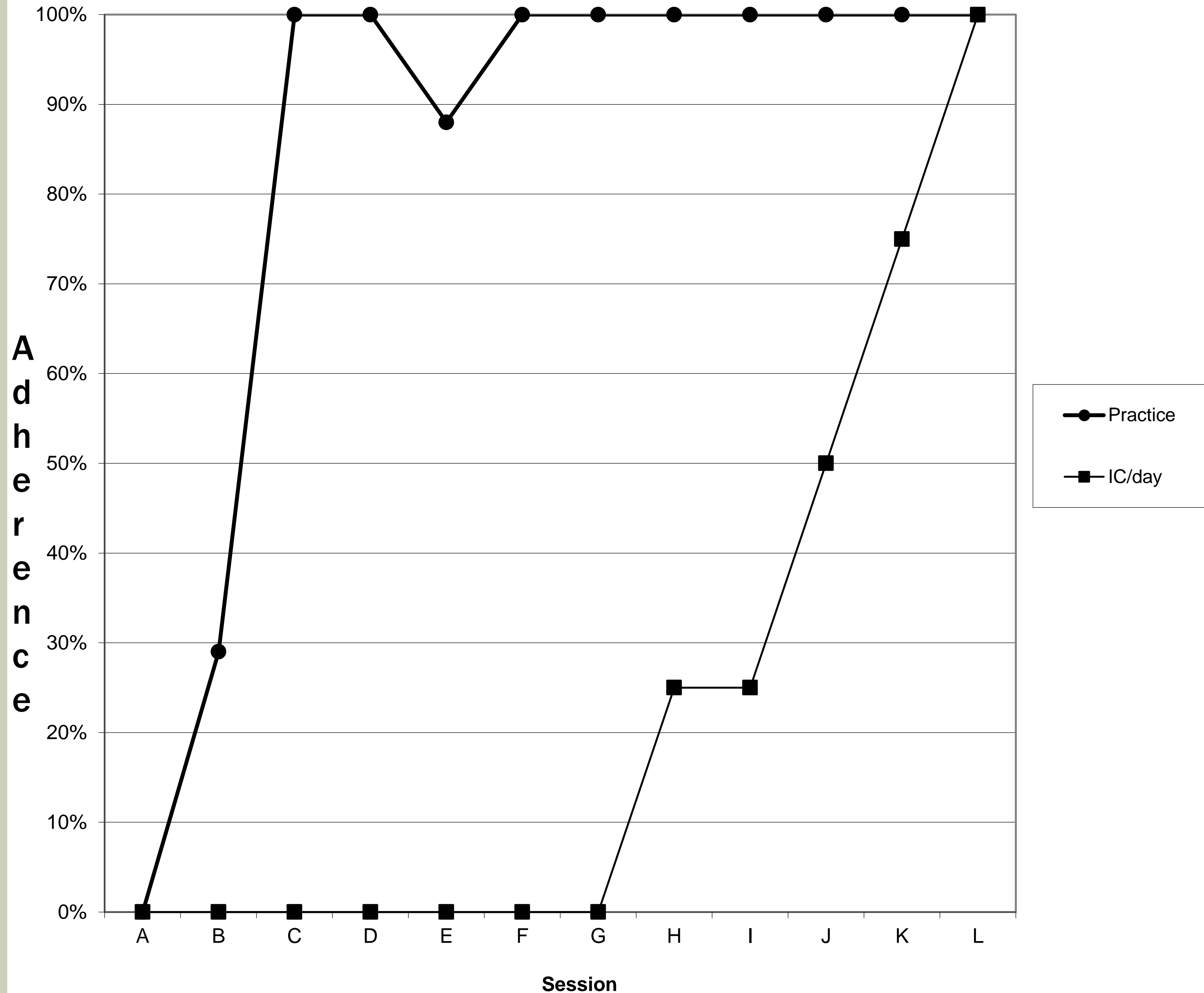
- Parents who can recall recommendations have higher probability of adherence
- Practice a script
  - Intro: "We covered a lot today and I want to make sure that I said everything clearly."
  - Prompt: "What <did we discuss today?> <do you need to do next?>"
  - Corrections (if needed): "Yup—not enough coffee today ☺ and I did not say exactly what I needed to. Here is the plan…"

CASES: COURSE OF TREATMENT

CASE 1: AARON

- 10 1-hour sessions over 5 months
- Move to next step: >80% adherence over 1-2 week period

Visit	Homework
A	Practice distraction
B	Practice CIC prep
C	Practice CIC prep
D	Add slight insertion/immediate withdrawal of tubing
E	Insert ¾"; hold for slow 5
F	Insert ¾"; hold for slow 10
G	Insert tubing to bladder neck
H	Full cath x1/day
I	Full cath x1/day
J	Full cath x2/day
K	Full cath x3/day
L	Full cath x4/day



Adherence
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
A
B
C
D
E
F
G
H
I
J
K
L
Session
Practice
IC/day

CASE 1: CONCLUSION

- Once cathing frequently, shift to relapse prevention
  - Problem solving strategies to complete CIC outside of home
  - Bringing in Dad more
- Elements used
  - Write it down
  - Behavior management
  - Rewards

Wrap Up Session

1. **General behavior management with cathing**
   a. No retreats! Once you ask, follow through. *This is the magic bullet!*
   b. Cathing=normal routine now. However, just like with all other 'normal' routines (like doing chores or showering), some reinforcement is helpful.
   c. If something interferes with cathing, you already know how to consult with urology and problem solve. This is crucial and you know how to do this very well—even though it is hard in the moment.

2. **Bringing Dad into the mix**
   a. Dad's 'poker face' is crucial.
   b. Gradually bring Dad in. Have him start with smaller steps and gradually build up.

3. **Adolescence**
   a. As Aaron grows up, it will be important to think ahead as he develops. This may lead to temporary bumps in the road and will require your problem solving skills.
   b. Think ahead—when Aaron is 11 or 12, will he be ready/willing to cath alone? How will you ensure that he is ready to cath and that he is doing it routinely?

CASE 2: ELLA

- 37 sessions over 26 months—still in treatment
- Shift in treatment goals
  - Anxiety/coping
  - Sit schedule
  - CIC
  - BM Regimen
  - ADHD Evaluation

NONADHERENCE IN MIDST OF DESENSITIZATION

OBJECTIVE:

Data Period	Days	Average void/day	Notes
Baseline: 9/18-9/24/13	7	2.4 ounces/day	
Week 1: 9/25-10/01/13	7	3.9 ounces/day	8 voids; Range of 1/2 to 8 ounces per void
Week 2: 10/02-10/09/13	7	No recording	6 voids
Week 3: 10/09-10/16/13	7	2.0 ounces/day	6 voids; 15 sits during week; decreased variability in range of voids (2-4 ounces); mother reported several other smaller voids recorded as under 1/2 ounce
Week 4: 10/17-10/22/13	7	3.1 ounces/day	5 voids; 11 sits during week; voids ranges in volume from 2-8 ounces (3 of these were 3.5-4 ounces)
Week 5: 10/23-10/29/13	7	4.8 ounces/day	7 voids; 11 sits during week; voids range in volume from 1-8 ounces
Week 6: 10/30-11/05/13	7	7.0 ounces/day	12 voids; 15 sits during week; voids range in volume from 1-8 ounces
Week 7: 11/06-11/13/13	7	Not available	Sticker chart not used due to surgery/botox injections
			Sticker chart targeting voiding not currently used due to medical complications.
Week 10: 12/11-12/18/13	7	2.45 ounces/day	9 voids over 10 sits; voids ranged in volume from 0.5-7 ounces
Weeks 11-current: 12/19/13-current		No recording	Per mother, Pediatric Urology recommended stopping sit times during visit in late December 2013
3/26-4/1/14	7	9 ounces/day	8 voids ranging in volume from 6-10 ounces; mother also recorded amount drained after void in toilet and 0-4 ounces were recorded.
4/2/-4/8/14	7	3.4 ounces/day	3 voids ranging in volume from 6-10 ounces; Amount drained after each void was 0 oz, 1/2 oz and 1 oz. Stool placed in toilet on 6 occasions.
4/9-4/16/14	7	0 oz/day	Ella refused to sit at all in the preceding week
4/17-present		No data recorded	

TREATMENT COURSE

Visit Number	
~2	Started on Zoloft
4	Report filed with Child Protective Services resulting in in-home therapist
8	Started botox injections
10	Consult with Psychiatry due to anxiety; allegations of physical abuse (unfounded); in-home therapist still has family has open case
	CIC = goal by medical team
12	1 minute talk about cathing
14	Push for more regular school schedule/sleeping patterns; talk about cathing for 4 minutes
17	Joint visit with NP from Pediatric Urology to review teaching
18	Patient and mother watch CIC educational video; shift from patient saying “no cathing” to expressing preferences about how it can get done

TREATMENT COURSE

Visit Number	
19	0% adherence to desensitization tasks at home; no parental monitoring; review behavior management strategies
20	100% adherence; increased parental participation
21	Holding tubing close to point of insertion
22	Continued strong adherence; 10 practice sessions (prep + hold tube close to point of insertion) over 14 days
23	Insertion ¼" to ½"; practiced 12 times over 21 days + 8 sessions of relaxation

SESSION 24: COMBINED VISIT WITH PEDIATRIC UROLOGY

- Prep in session 23
  - Choice points: presence of psychology in room; relaxing music; lighting; how to request breaks; asking for NPs to count to 3 before proceeding to next step
  - Non-negotiables: presence of mother; being respectful
  - Comments from Ella: “not so bad” and expressing confidence that she can do this.
- Session 24: Success!
- Follow up:
  - Some decreased frequency of cathing at beginning
  - Currently: every 4 hours including at school

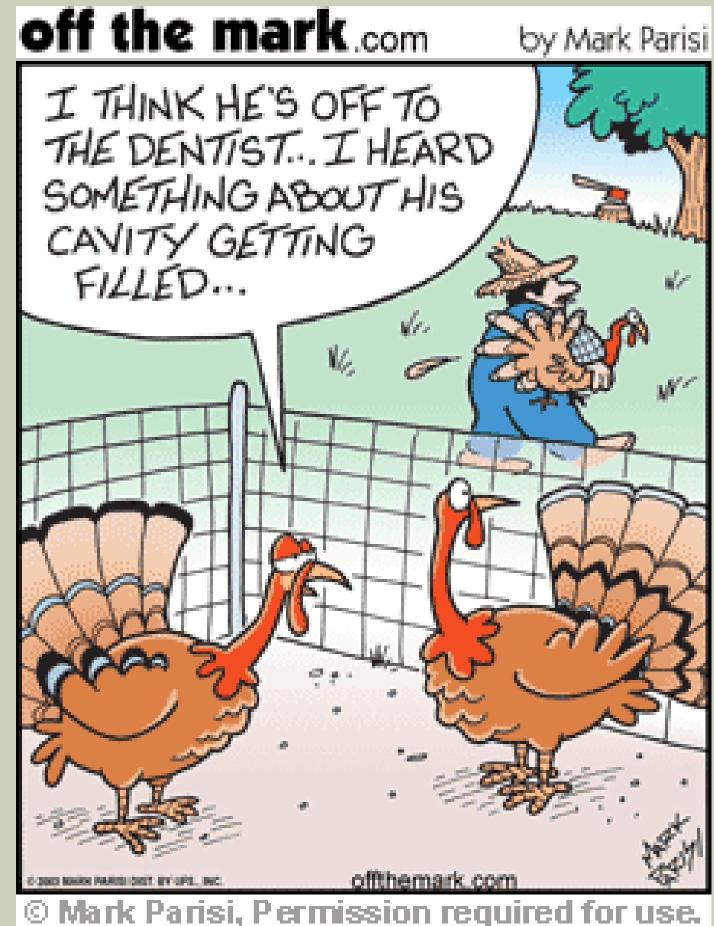
CASE 2: CONCLUSION OF CIC AS TREATMENT GOAL

- Elements used
  - Rewards
  - Write it down
  - Constant review of behavior strategies
  - Consultation with medical team about pace
  - Consultation with other systems (school; PCP)

RED FLAGS & RESOURCES

RED FLAGS

- Child
  - Oppositional in multiple areas or settings
  - Anxiety resulting in tantrums, aggression
- Parent
  - Mental health concerns: anxiety, depression
  - Significant lack of support
  - Tension around topic



RESOURCES

- Health/pediatric psychologists
- Community psychologists:
  - Uses behavioral training
  - Comfortable with desensitization procedures

QUESTIONS?

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