Teaching Cognitive Behavioral Therapy to Improve Quality Life and Pain in Children with Chronic Disease

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Goals of Presentation

• How and why a CBT based on identifying appropriate locus of control is a good match for treating depression and pain in children with physical illness?

• How CBT was modified to target coping with chronic physical illness, improving quality of life, and pain?

• What are the active ingredients in CBT content and process?
What is Cognitive Behavioral Therapy (CBT)?

- CBT seeks to identify and modify maladaptive beliefs, attitudes and behaviors

- Time-limited and problem focused

- Building or enhancing coping skills
  - Restructuring cognitive distortions
  - Altering arousal patterns
  - Modifying stimulus environment
  - Changing contingencies of reinforcement

- Maintenance of skills following termination
Negatives bring us down.
Negative behavior.........Negative thought.........Negative emotion
I’m not studying................I’ll never past the test........hopelessness

Positives bring us up.
Positive behavior.........Positive thought......Positive emotion
Study for test...............I can do well if I try........confidence
CHILD FACTORS
• Motivation
• Comorbidity
• Flux

FAMILY FACTORS
• Personality
• Time & stress
• Jiffy-lube model

THERAPIST FACTORS
• Training / beliefs
• Loyalty / incentive
• Time & caseload

CLINIC FACTORS
• Rules, constraints
• Case assignment
• Staff factors

REAL-LIFE FACTORS
• Problem/crisis of the week
• Serious loss, trauma, risk
• No adult who cares

OUTCOME
Weisz’s Skills and Thoughts Model

- Skill deficits and cognitive habits may generate sad affect in response to adverse stressful or ambiguous life events

- **Skill deficits** = poor activity selection, poor self-soothing, unengaging social style

- **Cognitive Habits** = negative cognitions, rumination, perceived helplessness hopelessness, lack of control

- Gain control over mood by developing skills to cultivate primary and secondary control

  - **Primary control** = changing objective conditions to make them fit wishes

  - **Secondary control** = changing expectations to adjust to objective conditions and thus control their subjective impact
Primary and Secondary Control Enhancement Training (PASCET)
ACT and THINK Chart

- **A** Activities
- **C** Calm and Confident
- **T** Talents

- **T** Think Positive
- **H** Help from Friend
- **I** Identify Silver Lining
- **N** No Replaying Bad Thoughts
- **K** Keep Trying
PASCET Coping Skills

• Ten coping skills

• Two broad groupings
  Primary............ 5 “ACT” skills
  Secondary........ 5 “THINK” skills

• Try all ten, then pick just a few that work
PASCET Program for Youth Depression

When I start to feel bad, I can do 2 kinds of things to feel better:

**ACT**..........and..........**THINK**

**A** Activities. Do activities that solve problems [use S-T-E-P-S], activities I enjoy, activities with someone I like, activities to stay busy, & activities to help others.

**C** Calm and Confident. Stay calm—make myself relax. Stay confident—show a positive self.

**T** Talents. Develop a special talent or skill. Set a goal, plan steps to reach the goal, then practice, practice!
PASCET Program for Youth Depression

When I start to feel bad, I can do 2 kinds of things to feel better:

ACT.........and..........THINK

T  Think Positive.  No negative thinking allowed.
     Change my B-L-U-E, negative, unrealistic thoughts into positive, realistic thoughts.

H  Help From a Friend.  Think things over with someone I trust.

I  Identify the “Silver Lining.”  Figure out what’s good about my situation.

N  No Replaying Bad Thoughts.  Stop thinking about things that make me feel bad. Get my mind on something else.

K  Keep Thinking—Don’t Give Up.  Keep trying ideas from my ACT & THINK chart until I feel better.
PASCET CBT SESSIONS

• **Session 1**: Introduce PASCET model, build alliance, learn problem-solving approach.
• **Session 2**: Choosing activities you enjoy alone and with others
• **Session 3**: Relaxation techniques to counter pain and anxiety in social situations
• **Session 4**: Showing positive self, improving social skills
• **Session 5**: Developing talents and skills
• **Session 6**: Addressing negative cognitive distortions alone and with help of others
• **Session 7**: Positive reframing with less negative counter-thoughts
• **Session 8**: Developing several cognitive behavioral plans to address problems
• **Session 9-12**: Review and personalize skills learned.
Coping with Physical Illness
Considerations in Physically-ill Adolescents

- Physiological effects of illness
- Psychological reaction to loss of healthy self
- Increased family conflict
- Missed social opportunities
- Fears about illness and its treatment
- Sense of self-efficacy
Inflammatory bowel disease (IBD) as model illness:

• Chronic, debilitating illness with unpredictable course and complicated treatment.

• Problems with social isolation, family conflict, school absences.

• High rates of depression compared to normal controls and other physical illness groups

• Significant relationship between depression &
  – IBD severity
  – Exogenous steroids
  – Pain
  – Medication adherence
Developing a CBT-based Approach for Depressed Adolescents with IBD:

• Enhance CBT approach to treat depression in adolescents with chronic physical illness with narrative illness & family education components (Step 1)

• Apply enhanced CBT in practice setting using single case applications (Step 2)

• Assess the effects of enhanced CBT under controlled conditions in depressed adolescents with IBD (Step 3)

• Randomized trial of enhanced CBT compared to active control group in depressed adolescents with IBD (Step 4)

Deployment-Focused Model for Psychotherapy (Weisz 2002)
Modification of PASCET for Depression in Youth with Physical Illness

- Focus on appropriate locus of control
- Integrate physical illness narrative into treatment goals
- Application of CBT skills to physical illness-related problems such as medication adherence
- Incorporate education about depression and IBD
- Family/parent involvement intensified in developmentally-appropriate way (Beardslee model 1993)
- Hypnosis for anxiety, pain, immune functioning
- Flexible deliver- phone, medical visits, inpatient bedside
Illness narrative is the patient’s perception of their illness and illness experience.
Importance of Physical Illness Narrative

• Individual adjustment to illness strongly associated with perceptions and experiences with illness

• Relationship between cognitive illness perceptions and coping, mood, functional adaptation, and medication adherence.

• Patients cluster ideas about illness into 5 components (illness narrative; Leventhal 1998):
  – Identity
  – Cause
  – Time-line
  – Consequences
  – Cure-control
Illness Narrative

What do you call your problem?

What do you think caused your problem?

Why do you think it started when it did?

What does your sickness do to you? How does it work?

How severe is it? How long do you think you will have it?

What do you fear most about your illness?

What control do you have over your illness?
Top IBD Patient Concerns

• Ostomy bag
• Medication effects
• Uncertainty
• Surgery
• Damaged self
• Pain/suffering
• Bathroom Access
• Diet
• Being burden
• Reaching full potential
Issues Unique to Children and Adolescence

- Development- cognitive, emotional, self, puberty
- Child versus parent report
- Parental modeling of sick role behavior
- Adolescents more influenced by environment (modeling, prompting, rewarding, punishing)
Importance of Perceived Control

- Youth with depression have negative cognitive distortions, including more external locus of control for negative events (Hammen & Goodman-Borwn 1990; Weisz et al., 1986).

- Children with IBD with less effective coping skills overall and less flexible self-coping compared to healthy children (Gitlin et al., 1991; van der Zaag-Loonen et al., 2004).

- Youth with IBD have higher external locus of control compared to children with other physical illnesses, and poorer coping with their IBD possibly because IBD is relatively unpredictable (Engstrom, 1999).
Importance of Cognitive Formulation

- Brief case summary (3 sentences)
- Chief Complaint
- Problem List (Depression and Physical Illness)
- How C shows Depressed Feelings (Behaviors)
- Core Beliefs (Cognition)
- Precipitating Events (Triggers)
- Strengths/Assets
- Working Hypothesis
- CBT skills most likely to help
ACTS for Adolescents

• A  Activities (2 sessions)

• C  Calm (Relaxation) (2 sessions)

• T  Think positive (2 sessions)

• S  Sleep hygiene (1-2 session)
Youth Session Guidelines

• 9 structured sessions covering A&T skills
• Stay with each skill until child clearly gets it or seems unlikely to
• Can sometimes skip a skill if clearly not a problem (e.g., Session 5, talents & skills)
• From Session 10 on, content and practice assignments are completely individualized
• Use thermometer often to stress key idea
Elements of CBT Session

• Therapeutic Alliance
• Session Format
  – Introduce skill
  – In-vivo practice
  – Assign homework
  – Reinforcement scheme
• Flexibility and creativity key
• Reinforce PRACTICE! PRACTICE! PRACTICE!
Youth Session 1: First Steps

• Describe structure, sequence of program
• Introduce Practice Book
• Educate about IBD and depression
• Probe Illness Narrative
• Transition to Problem Solving S-T-E-P-S...
Education: Offering patients a validating explanatory model

Cytokines

Tension and stress

Pain

Muscle spasm in gut wall

Nervous control of gut

Underlying malfunction

Steroids

Guthrie E, Thompson D. BMJ 2002;325:701-703
ACT: Teaching Problem-Solving

- **S**tay calm and say what the problem is
- **T**hink of solutions
- **E**xamine each solution- what is good or bad about it
- **P**ick one and try it.
- **S**ee if it works. If no, try another solution.
ACTS Skill 1: Problem-Solving

• Purposes:
  – Counter helpless resignation; teach kids they have more control than they may think
  – Teach that nearly all problems can be broken down and addressed systematically
  – Provide a versatile coping skill that can be used with a broad variety of stressors and “crises of the week (COWS)”
S-T-E-P-S to Problem Solving

• S Stay calm and say what the problem is
• T Think of solutions (many!)
  – 1____  2____  3____  4____  5____  6____
• E Examine each one (How good, bad?)
• P Pick one and try it out
• S See if it worked (If not, try another one)
ACTS Skill 2: Activity Selection

• Purposes
  – Help individuals see relation between what they do and how they feel
  – Get them to identify multiple activities that are reliably mood enhancing for them
  – Teach them to exert control over mood by choosing to do their mood enhancing activities
ACT Skill 2: Activity Selection

• Kinds of Activities that can work:
  – Simple, free, anytime, anyplace- choose 10
  – Doing things with someone we like- choose 3
  – High activity level, staying busy--group, club- choose 3
  – Altruism: helping someone else (combat self-focus)
  – Exercise, yoga
Activity- Exercise

- Reduces stress and depression

- Low intensity better than exhaustive program

- Exercise better than sedentary life style
ACT Skill 3: Calm (Relaxation)

• Purposes
  – To address the tension often associated with depression (frequently accompanying worry)
  – To teach that an uncomfortable state in their bodies, like other adverse conditions, may be amenable to their control
  – To teach two approaches: Deep muscle with imagery and “secret calming”
  – 4-4-8 Breathing
CALM: Breathing pattern before and after practice using biofeedback device

Relaxation/hypnosis shown to decrease autonomic arousal via stimulation of the parasympathetic nervous system
Relaxation

Dialing down pain
Enhance immune function
Model of Functional Pain

Psychosocial factors
- Life stress
- Psychological state
- Coping
- Social support

Early life
- Genetic
- Environment

Physiology
- Central and peripheral nervous system function
- Brain-gut axis
- Intestinal function (secretory, motor, sensory, inflammation)

IBS
- Symptoms experience
- Illness behavior

Outcome
- QOL
- Daily function
- Health care use
- Medications
- Work absenteeism
Factors Modifiable by Intervention

PSYCHOSOCIAL INTERVENTIONS

Psychosocial factors
- Life stress
- Psychological state
- Coping
- Social support

Early life
- Genetic
- Environment

Physiology
Central and peripheral nervous system function
Brain-gut axis
Intestinal function
(secreory, motor, sensory, inflammation)

IBS
Symptoms experience
Illness behavior
Outcome
- QOL
- Daily function
- Health care use
- Medications
- Work absenteeism
**Switchbox**: Explain how pain is transmitted by nerves from various parts of the body to the brain, which then sends a pain message back to the body. You can use an analogy of wires connecting from the body parts that are in pain to the brain if the child is too young to understand the concept of nerves. Ask the child to provide colors for the nerves/wires. Then provide a dimmer switch that the child can access in their brain that can turn down the pain to a level that is suitable for the child. Remind the child that they are in control of the switch that controls the pain. Have them practice turning down their pain reminding them that they are in charge of the pain and can control at any time they see fit.
Creating effective hypnotic imagery

- Encourage visualization in all 5 senses
- Explicitly incorporate contrasts
- Encourage details
- Ask questions to increase vividness
- Use color liberally
- Provide plenty of detailed guidance … but also encourage creative additions/edits
- Give suggestions for enhanced clarity and vividness
- Tie the imagery to the desired changes
- With children, incorporate plenty of movement/action
Examples of elements of useful GI metaphors/images

- Protective cabin or a cave when the storms howl outside
- Secluded garden
- Private island
- River
- Healing light (associated with warmth or coolness)
- Protective coating/shield/forcefield of the gut wall
- Waves lapping against the beach
- Rocking motion (calming, soothing) boat, hammock, train, etc.
- Melting ice cube
- Magic drink
- Rubber band
- Amusement park slide
- Healing, soothing hand
IBD Hypnotherapy Protocol

• **Session 1**: Obtain history of IBD and illness narrative; happy place/laughing place/safe place. Heroes, favorite video game, TV show. Educate about immune system and link hypnosis to strengthening guard cell’s ability to counter the killer cells activated during an IBD flare.

• **Session 2**: Review immune functioning in IBD. Teach about breathing and muscle relaxation. Guided imagery for child to look inside bones (factory) to make less killer cells and more guard cells and send them into bloodstream to act at site of inflammation. Guard cells provide protective coating to help heal and be less sensitive to pain. Imagine intestine becoming smooth and free of inflammation-what it would feel like. Tape to practice.
Hypnotherapy for IBD-Cont.

• **Session 3:** Same as Session 2. For pain control, dimmer switch imagery, plowing out pain or imagining painful area turning colors or temperature. Use sensory prop (hand on abdomen). For motility, change flow of river. Individualize based on child’s symptoms and associative imagery provided in Session 1.

• **Session 4:** Same as Session 3. Also add happy or special place with choice of comfortable safe feeling places. Continue to juxtapose relaxed feeling with ability to have less discomfort and return of normal GI functioning to have more relaxed control of fighting back at IBD flare-up and returning to life.
ACTS Skill 4: THINK: BLUE Chart

• How to catch yourself having a negative thought?

  B - Blaming yourself
  L - Looking for the negative
  U - Unhappy guessing
  E - Exaggeration
<table>
<thead>
<tr>
<th>Negative Thought</th>
<th>Mood Rating</th>
<th>BLUE label</th>
<th>Positive Counter-thought</th>
<th>Mood Rating</th>
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Cognitive Distortions

- **Catastrophizing** “Life will always be horrible”  
  \[
  \text{E}
  \]

- **Disqualifying the positive** “You’re just being nice”  
  \[
  \text{L}
  \]

- **Jumping to conclusions** “I’m not going out with my friends because I know they don’t want me to”  
  \[
  \text{U}
  \]

- **Magnification** “My friends will reject me because I have IBD”  
  \[
  \text{L or E or U}
  \]

- **Selective Abstraction** You are having fun at a party until someone asks you about your weight-”My evening is destroyed”  
  \[
  \text{L}
  \]

- **Personalization** “It is my fault”  
  \[
  \text{B}
  \]
Double Bubble

BLUE, Negative Thoughts

Positive, Realistic Thoughts

Situation that made me feel bad ____________________

_____________________

_____________________

_____________________
ACT Skill 5: Sleep Target
Relaxation Therapies for Reducing Arousal

• Progressive muscle relaxation
• Biofeedback- EMG & EEG
• Guided imagery
• Meditation
• Hypnosis

• Best suited for sleep onset problems
Brief behavioral treatment of insomnia: Four easy steps! (Buysse)

- Reduce your time in bed
- Get up at same time every day of the week regardless of how much you slept night before
- Don’t go to bed unless you’re sleepy
- Don’t stay in bed unless you’re asleep (Eliminate iphones, caffeine, worries, bad bed)
- Working with nocturnal diarrhea/ostomies

GOAL: Time in bed = Actual Sleep time
Behavioral Approach to Sleep Disturbance (Manber)

**BEHAVIORAL**
Alter sleep-disruptive habits
- Excessive time in bed
- Irregular sleep schedule
- Sleep incompatible activities
- Conditioned arousal

**COGNITIVE**
Alter unhelpful beliefs
- Unrealistic sleep expectations
- Sleep misconceptions
- Sleep anticipatory anxiety
- Cognitive arousal

**EDUCATION**
Improve sleep knowledge and hygiene
- Inadequate sleep hygiene
Practice, Practice, Practice

• Individualize skills both for current problems and anticipated problems in future (e.g., having another IBD flare up)

• Re-probe illness narrative

• Move from didactic/socratic to less active with child being more in charge
Parent Involvement

• Get essential information about child’s problems and perspective on physical illness

• Train parents to be CBT coaches

• Help parents with contributory problems-communication, advocating for school, treating parental depression
Parent Session 1

Parents as Partners

• Getting parent’s perspective
• Introduce ACT and THINK
• Parental reaction to IBD
Parent Session #2: Parents as Collaborators

- Review child’s progress to date
- Trouble shoot any new problems (e.g., not doing practice)
- Address parent role (e.g., monitoring risk)
- Firm up partnership as co-therapist
**Parent Session #3**  
**Parents as Coaches**

- Review achievements
- Review main themes, including *depression triggers, best-fit skills*
- Discuss & plan for future risks
- Praise parent for commitment to child
- Parent: coping helper
Beliefs Associated with CBT Failure

• My therapist does not understand me
• Change is not possible (It’s no use!)
• I don’t have the ability
• My child is doing this on purpose.
Positive Prognostic Factors

• Therapist skill level
• Positive patient engagement
• 4 most “active” skills
  – Problem-solving STEPS
  – Activities
  – Relaxation/hypnosis
  – Cognitive distortions
Relapse Prevention

- Review effective interventions, techniques, skills
- Booster sessions
- Attend to comorbid conditions
- Remember pharmacotherapy options
Case Presentation

• 14 y o white male in 9th grade living with parents
• Ulcerative colitis x 4yr
• New onset x 6 month of feeling sad, easily frustrated, decreased motivation and energy, “I feel like a bad person”, “I wish I was dead” and stomach aches

• Downward shift of grades, isolated from friends, school avoidance
• Increased difficulty negotiating conflicts with peers
• Significant tension and fighting between parents with frequent threats of divorce
• Mother with depression, father with anxiety and alcoholism.
• Father unemployed
K’s Formulation

• **Chief Complaint:** “I’m doing ok except when I have pain, then I have a bad day.”
• **Problem List**
  – Feeling sad, frustrated
  – Coping with stomach pain
  – Decreased motivation
  – Low self esteem “I’m bad person” “I’m too short”
  – School avoidance and declining grades
  – Isolation from peers
  – Interpersonal difficulties with peers
  – Coping with parental marital conflict
  – Modeling of sick role/enabling by father and withdrawal by mother
  – Indecisive about future plans “I don’t know”
K’s Formulation-Continued

• **How C shows Depressed Feelings?**
  Somatization, avoidance of peers, withdrawal from activities, lower frustration threshold when forced to interact with peers.

• **Core Beliefs**
  – I am bad person- I’m stupid and short.
  – It is easier just to sit home and watch tv, just like my dad
  – My stomach ache causes my bad moods
  – There is nothing good in my life

• **Precipitating Events**
  – Increased fighting between parents
  – Conflicts with peers
  – Academic struggles

• **Strengths/Assets**- bright, sense of humor, Has skills in video games, soccer and computers, wants to do well in school and be liked by his friends
Working Hypotheses

• **Skills and Thoughts Model**

K has a number of skill deficits like social interaction with peers, eliciting social support from adult figures in his life, difficulty self-soothing with increased focus on pain, and difficulty setting goals in his different functional domains.

K has a number of maladaptive cognitive habits such as lack of perceived control over his environment, negative cognitive distortions, hopelessness and helplessness. Together these negative behaviors and thoughts make him more vulnerable to feeling depressed.
CBT skills most likely to help

Skills and Thoughts Model- PASCET

• Teach coping skills to elicit PRIMARY control
  – Scheduling fun activities alone and with others
  – Teach problem-solving approaches in steps
  – Relaxation to help counter pain
  – Showing more positive self in social situations

• Teach ways to change thinking in situations that can’t be changed to elicit SECONDARY control
  – Thinking less negatively by identifying cognitive distortions and replacing with more positive thoughts either alone or with the help of others
  – Mood monitoring to link emotions, thoughts and behaviors.
Biopsychosocial Model to Improve QOL

Psychological
- Depression
- Locus of Control
- Coping Style
- Illness Narrative

Social
- Social Support
- Family Environment

Biological
- Inflammation
- Steroids
- Pain
- Sleep
Coping with Stress
Responding vs Reacting

Perception Appraisal

External Stress

Stress Rx

BODY SYSTEMS

Break down

Recovery of mental and physical homeostasis

Telling Story
Cognitive Reappraisal
Behavioral Activation
Lifestyle Changes
Relaxation

Maladaptive Coping
Model for Integrating Behavioral Treatment into Pediatric Medical Care

• Our results show feasibility and benefit of screening for depression during medical visits.

• Feasibility of treating depression with CBT, even if related to physical illness activity.

• Feasibility or coordination of behavioral visits with medical visits or procedures.

• Algorithm of treatment with CBT followed by pharmacotherapy by mental health personnel nested in medical clinic.
Integrating CBT into Medical Practice

• Decide your treatment targets early
• One skill per visit 10-15 minutes
• Reinforcing practice
  – Parents
  – PCP/pediatrician
• Workbook as reinforcement
## Biopsychosocial Treatment

<table>
<thead>
<tr>
<th>BIOLOGICAL</th>
<th>PSYCHOLOGICAL</th>
<th>SOCIAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treat underlying organic problem</td>
<td>Cognitive restructuring/ Monitoring symptoms</td>
<td>Education</td>
</tr>
<tr>
<td>Exercise</td>
<td>Behavioral-activation/distraction</td>
<td>Enable/expect return to life</td>
</tr>
<tr>
<td>Medications</td>
<td>Conflict resolution</td>
<td>Family/Parent therapy</td>
</tr>
<tr>
<td>Alternative-acupuncture</td>
<td>Hypnosis/Meditation</td>
<td>School/ work modification</td>
</tr>
<tr>
<td>Sleep</td>
<td>Activity scheduling</td>
<td>Social network</td>
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