Approach to Newly Diagnosed IBD in Children and Adolescents: Mental Health Support

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November 3, 2018
Disclosure: Szigethy

• Sources of Funding
  – PCORI grant, PI
  – NIH grant, Co-I
  – Sherman Prize recipient
  – APPI royalties as book editor
Objectives

1. Evaluate risk factors for increased stress and poor coping with pediatric IBD

2. Discuss prevention strategies for psychological stress for the child and family

3. Provide framework for a health care delivery model that integrates behavioral health services and transition to adult care for pediatric IBD patients
What is stress?

• Stress results when something that happens to you exceeds the capacity of your mind to deal with the event effectively.

• The mental and physical effects of stress are due to the elevation of stress hormones and related biochemical cascades that occurs when the stress related areas of the brain are activated.
Coping = Adaptation

• “Collection of purposeful, volitional efforts that are directed in the regulation of aspects of self and the environment under stress” (Compas, 2001)

• Linked to regulation of psychological and physiological (INTERNAL) processes including emotion, behavior and cognition and interactions with others and environment (EXTERNAL) (Skinner, 1994, 2007)

• Coping directly correlates with adherence, disease outcomes, and psychosocial adjustment (Compas 2012)
Domains of Adaptation

- Cognitive
- Emotional
- Social
- Parents
- Life Stress
- Physical

Bousvaros et al., 2006; Greenley et al., 2010; Mackner et al., 2013
Physical

Risk
• More aggressive IBD course
• Symptoms
• Growth failure/puberty delay
• Surgery
• Steroids

Consequence
• Lost developmental opportunities - school, peers
• Malnutrition-eating disorders
• Shame, depression, poor sleep
• Low self esteem, bullying
• Anxiety, Traumatizing
• Cognitive slowing, irritability, poor sleep

Mamula et al., 2017
Cognitive

Challenges

• Piaget Developmental Stages
  – Pre-operational (ages 2-7) magical thinking
  – Concrete operational (ages 7-adolescence) inductive reasoning
  – Formal operational (adolescence-) abstract thinking, deductive reasoning

• Illness Perception
  – Pessimistic
  – Locus of Control
  – Perceived disability

• Negative cognitions
  – Catastrophizing

Consequences

• Increased anxious anticipation and illogical processing of IBD and its treatment

• Associated with depression and worse medical outcomes and poor quality of life

• Greater pain, anxiety and somatization
<table>
<thead>
<tr>
<th>Challenge</th>
<th>Consequence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grief Reaction</td>
<td>Adjustment disorder- time-limited (weeks); if longer and with functional impairment, rule out depression.</td>
</tr>
<tr>
<td>Anxiety</td>
<td>Health-related, generalized, social and separation types.</td>
</tr>
<tr>
<td>Depression</td>
<td>Learned behavior (modeling)</td>
</tr>
<tr>
<td>Irritable</td>
<td>Inflammatory causation</td>
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<tr>
<td></td>
<td>Cannabis self-medication</td>
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<tr>
<td></td>
<td>Behaviors – defiant, tantrums</td>
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</tbody>
</table>
Common Behavioral Conditions

• Anxiety disorders (GAD, panic d/o, separation and social anxiety) 20-50%

• Chronic abdominal pain 30-80%

• Major Depression 25-40%

Mayer 2001; Shah 2014; Mikocka-Walus 2016; Gradus 2017; Szigethy 2007; 2009
Major Depression

- **Mood** (irritable or depressed) or **Anhedonia**

5 of following symptoms:
- Fatigue .................self-pity, pessimism
- Change in appetite.......tearful
- Change in sleep.......social withdrawal
- Reduced concentration ....lack of reactivity to environmental events
- Motor retardation

- Thoughts of death or suicide
- Guilt
- Worthlessness
- (Helplessness)

Over a two week period

INFLAMMATION

High sensitivity (87%) and specificity (97%) for depression in medically ill

DSM-V; Rapp 1989
Social

Challenge

• Isolation from peers

• Adversity

• Lack of social support (family, community)

• Substance use (cannabis, opioids)

Consequence

• Delayed developmental milestones
  – Industry versus Inferiority in school, hobbies, sports (ages 5- puberty)
  – Identity versus Role Confusion (peers, dating, competition) (ages puberty – 19)

• PTSD, medical and mental comorbidity

• Worse outcomes- adherence, medical and mental

• Self-medication leads to substance misuse disorder and worse outcomes, including higher mortality

Wren et al., 2018
Parents/Caregivers

Challenges

• Parental reaction to IBD

• Parenting style
  – Absent
  – Over-protective
  – Solicitousness

• Parental psychopathology

Consequences

• Sends message of safety versus danger to child with positive and negative reinforcement of behaviors

• Adverse influence on child’s coping and autonomy.

• Inadvertent reinforcement of sick roll

• Worse medical and psychiatric outcomes in the child.

• Increased medical utilization

Giannakopoulos et al., 2016
Life Stress

**Challenges**

- Stress of IBD diagnosis

- **Major life stressors**
  - Trauma, abuse
  - Parental divorce/loss

- **Daily hassles of life**
  - Bathroom access
  - School expectations
  - Navigating peers

**Consequences**

- If long or traumatic then can lead to worse mental health sequelae

- More psychopathology and worse physical outcomes

- Poor adaptation of child

- Reduced medical adherence

- Poorer medical outcomes
Targets for Intervention

- Cognitive
- Emotional
- Social
- Parents
- Life Stress
- Physical

Whole Child
Helping Children and Families Cope

**ACTIONS**

- **Screening**
  - Mental Health
  - Maladaptive coping
  - Impaired functioning

- Developmentally appropriate education

- Brief interventions

- Parental assessment and guidance

- Community Resources

**CONSEQUENCES**

- Prevent psychiatric disorder
- Prevent opioid and cannabis misuse
- Optimizing development and adaptive coping

- Improve adjustment to IBD

- Behavioral conditioning reverses bad habits

- Parents can better help their child

- Treat psychopathology or more severe impairments in coping due to internal or external factors

Szegethy, 2014; Varni, 2017; Karwowski, 2009; Picoraco & Rosh, 2017
Behavioral Screening

- Brief- 4-10 items per domain
- Self-report measures ages 8-17
- Parent proxy measures ages 5-17
- Validated, normed cut-offs
- Computer adaptive testing item response

www.healthmeasures.net
Digital Screens embedded into EHR

- Tracking pain location, severity, interference and behavior over time
- Tracking anxiety, depression, sleep disturbance and physical functioning
- Patient completes through digital portal and measures are automatically scored and posted into the EHR
Coping with Pediatric Chronic Pain

Adaptive Coping

• Acceptance
• Cognitive reappraisal
• Distraction
• Problem-solving to deal with controllable sources of stress

Maladaptive Coping

• Passive coping (behavioral disengagement, self-isolation, catastrophizing)
• Parental solicitousness

Compas, 2012
Combating Bathroom Anxiety

- Anxiety ladders to overcome avoidance in small steps (positive reinforcement)

- Digital apps
  - *SitORSquat* app – rates public bathroom cleanliness
  - *Where To Wee* app – public bathroom locator
  - *Flush app* – bathroom locator
  - *Bathroom Scout* app – bathroom locator
  - *Fake Shower* app – sounds of water running
Improved Sleep

• Screen for sleep disturbance (PROMIS)
  – Too short (<7 hours)
  – Increased awakenings
  – Increased sleep latency
  – Reduced slow wave (deep) sleep (non-restorative)

• Sleep hygiene
• Behavioral techniques

The sleep drive & biological clock must be in sync for good sleep to occur.

Benhayon, 2013; Mahlmann, 2017; Szigethy 2015; Germaine, 2013
## Opioids and Cannabis

### Opioids
- Avoid use
- Taper and educate about harm (physical, addiction, death)
- Non-opioid alternatives - behavioral and pharmacological
- Screen for misuse (questionnaires, prescription drug monitoring programs, urine toxicology)
- Brief behavioral intervention
- Refer for addiction

### Cannabis
- Treatment agreement
- Track symptom targets (pain, nausea, appetite, diarrhea)
- Screen for misuse (gateway drug)
- Educate about side effects:
  - Neurocognitive deficits, future substance abuse, diminished driving performance, amotivation, paranoia, depression, brain development
- Refer for addiction

Phatak, 2017; Hoffenberg, 2017; Szigethy & Emerick, 2018; Wren, 2018
Brief Behavioral Strategies

• Brief collaborative discussions over multiple visits
• Reciprocal inhibition – two incompatible states cannot co-occur – (retrain breathing)
• Conditioned fear/anxiety can be subjected to counter-conditioning – (graded exposure)
• Involves shifting somatic attention and mastery of self-regulation – (cognitive reframing and behavioral activation)
• Behavioral activation – (exercise, hobbies)
Cognitive Behavioral Therapy (CBT)

THOUGHTS

FEELINGS

BEHAVIOR

PHYSICAL SYMPTOMS

(Environmental Factors)

(Vicious cycles?)

Lee David, 2016
# CBT for depression, anxiety, and chronic pain

<table>
<thead>
<tr>
<th></th>
<th>DEPRESSION</th>
<th>ANXIETY</th>
<th>CHRONIC PAIN</th>
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<tbody>
<tr>
<td><strong>Assumptions</strong></td>
<td>Skill deficits and negative cognitive habits maintain negative mood</td>
<td>Anticipatory worry and hyperarousal induce cycle of avoidance Conditioned fear can be counter conditioned.</td>
<td>Thoughts, behaviors, emotions and physical symptoms linked Vicious cycle especially if stressful environment</td>
</tr>
</tbody>
</table>
| **Specific Skills**     | Relaxation  
Cognitive reframing  
Behavior activation  
Sleep  
Problem-solving  
SMART goals | Relaxation/ Mindfulness  
Worry reversal  
**Exposure (ladders)**  
Positive Habits  
Sleep  
SMART goals  
Modeling | Relaxation/Mindfulness (self-soothing)  
Worry reversal  
Reverse catastrophic thinking  
Reverse disabled behavior  
Sleep  
SMART goals |
| **Developmental**       | Behavioral habits less set  
Make it fun  
Parental involvement | Automatic thoughts less set  
Make it fun  
Parental involvement | Cycles less engrained  
Make it fun  
Parental involvement |
| **Considerations**      |                                                                           |                                                                                                   |                                                                                                 |

SMART = Specific, Measurable, Attainable, Relevant, Time-bound

Weisz 1992; Regueiro, Greer, Szigethy, 2016; Banneyer, 2018; Levy 2016
Technology enhanced CBT for children and adolescents

- Providing standard manualized program online via computer or mobile device (self-guided or coached), virtual or augmented reality to supplement therapy and exposure practice

- Exist for adolescents or parental training for younger children for anxiety, depression and pain

- Similar or superior results to face to face therapy or wait-list controls

Palermo, 2009; Ebert 2015; March 2008; Khanna 2010; Donovan 2014; Freeman 2017; Parsons 2017
# Teen and Parent web-based CBT sessions

<table>
<thead>
<tr>
<th>Teen</th>
<th>Parents</th>
</tr>
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<tbody>
<tr>
<td>• Education about chronic pain</td>
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</tr>
<tr>
<td>• Recognizing stress and negative emotions</td>
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</tr>
<tr>
<td>• Breathing, relaxation</td>
<td>• Operant strategies</td>
</tr>
<tr>
<td>• Distraction</td>
<td>• Modeling</td>
</tr>
<tr>
<td>• Cognitive skills</td>
<td>• Sleep hygiene and lifestyle</td>
</tr>
<tr>
<td>• Sleep hygiene and lifestyle</td>
<td>• Communication</td>
</tr>
<tr>
<td>• Staying active</td>
<td>• Relapse prevention</td>
</tr>
</tbody>
</table>
Results of Digital Cognitive Behavioral Therapy versus Treatment as Usual for Anxiety and Depression in Emerging Adults

- Significant engagement in program (>75%)
- Significant clinical reduction in anxiety and depression
- Increased staff efficiency by 68%

Szeghely 2017; 2018
Transition ≠ Transfer to Adult Care

- **Transfer**: the move from one provider to another. **Single act**

- **Transition**: the purposeful, planned movement of patients toward independence, autonomy and self-advocacy. **Process**
  - Knowledge
  - Disease self-management
  - Emotional readiness
  - Self-advocacy
  - Available resources

- Developmental ranges of appropriate milestones
  - Age 12-14: Type of illness, Rx, Adherence
  - Age 15-18: Nutrition, self-management, reproductive health, insurance
  - Age >18: Self-management, New health providers

- Website Resources: CCF [www.justlikemeibd.org/](http://www.justlikemeibd.org/)

Blum RW 1993; Ferris, 2012
Preparing for Transition of Care

- Recognizing and reconciling differences in approaches to care between pediatric and adult providers
  - Differences in style
  - Differences in management
  - Differences in time allotted for office visit
  - Differences in procedures and sedation
- Planning for care at college/time away from home
- Balancing parent and patient interests
- Preparing the complete medical summary letter
Models of Integrated Medical-Behavioral Care

• New roles of pediatric medical staff
• New applications of technology
• Collaborative arrangements with community-based MH / SA / developmental specialists
• Co-location of specialist(s)
• Integration of specialist(s)
• Child psychiatry consultation by telephone, telemedicine, face-to-face
IBD Total Care Medical Home: Team-based, GI-point of care, patient-centered, coordinated care

Medical home attributes:
✓ Accessibility
✓ Comprehensive coordinated care
✓ Compassionate, culturally sensitive, patient- and family centered.
✓ Age 17- 65 with IBD

Regueiro, Greer, Szigethy, 2016
Stepped Digital Behavioral Care

IBD Total Care MEDICAL HOME

Tele-medicine Availability

- Behavioral Screening
- **digital** care management + **digital** CBT
- Social worker (behavioral therapy)
- Psychiatric consultation (medications)

REMOTE MONITORING OF PATIENT REPORTED SYMPTOMS

Medical nurses and nurse practitioners

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**IBD**
**Total Care**
**MEDICAL HOME**

**Behavioral Screening**
**digital** care management + **digital** CBT
**Social worker** (behavioral therapy)
**Psychiatric consultation** (medications)

REMOTE MONITORING OF PATIENT REPORTED SYMPTOMS
Total Care IBD: Outcomes

- High patient engagement
- High patient satisfaction
- Reduced provider team burnout
- Improved clinical outcomes
- Reduced opioid use
- Reduced medical utilization
- Successful transition of emerging adults

50.5 % decrease in ER visits total cohort*

*Based on clinical team analysis of EHR data.
Regueiro et al., 2017, 2018
## Summary

### Challenges
- Physical
- Cognitive and Emotional
- Social
- Parents
- Life Stress

### Mental Solutions
- Education; screening, treat root-cause
- Brief child and parent focused problem-solving and CBT
- Encourage social activity; Minimize video time
- Parent guidance
- Problem-solving, School 504 plans; Transition plans