Inflammatory Bowel Disease and the Adolescent: Psychosocial Considerations

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Objectives

- Review the unique struggles of adolescence.
- Understand the psychosocial burden of IBD.
- Understand the psychosocial challenges of the adolescent with IBD: Experiential Avoidance (EA) and Cognitive Fusion (CF).
- Review an approach to coping with IBD.

Do Adolescents with IBD Struggle with Anxiety and Depression Versus Healthy Adolescents?

What are the typical burdens of adolescence?

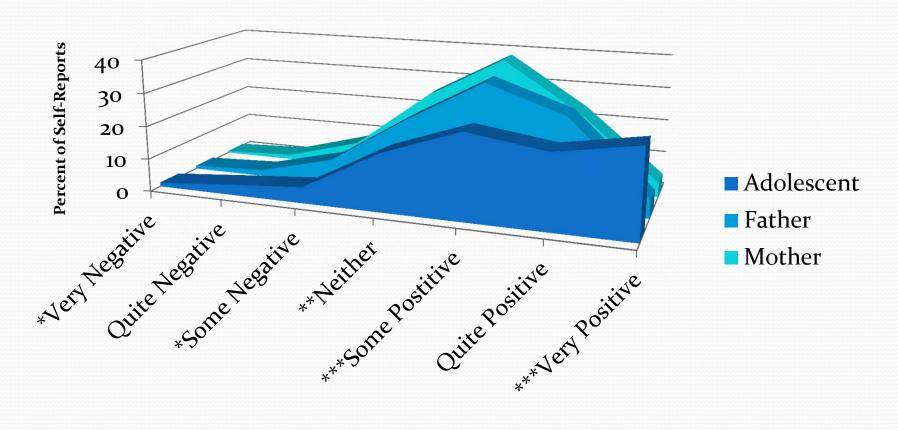
- Physical development
- Relationships: friends and groups
- School demands
- Social identity
- Role in the family

Youth and Adolescence Study (YAS)

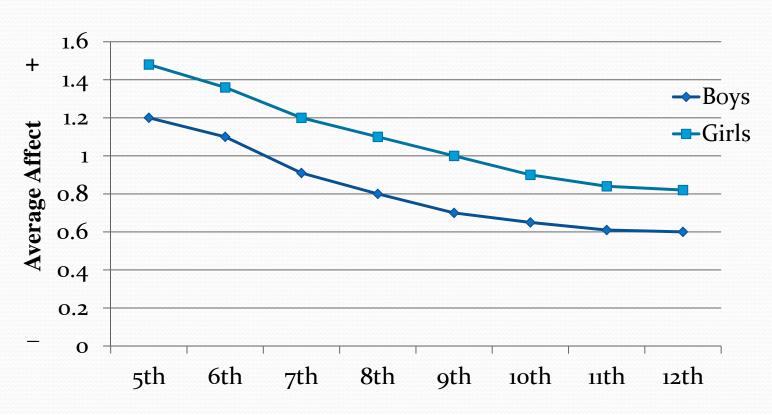
(Larson & Lampman-Petraitis, 1989)

- Randomly selected sample of 483 working and middle class, white, 5th-9th graders.
- Experience Sampling Methodology-pager system
- 220 were re-surveyed as 9th-12th graders.
- Combined with samples of poor and working class African-Americans (n = 262), and middle class 8^{th} graders from india (n = 100).

Distribution of Positive and Negative Affect by Family Members



Mean Affect Across Grades for Boys and Girls



(Larson et al., 2002)

- Puberty
- Stress
- Cognitive Changes

- Puberty: "Contrary to Popular Opinion"
 - Association between pubertal stage and emotionality are small in magnitude and appear to be strongest at the height of pubertal change: 5th to 6th grade.
 - Stronger relationship between pubertal development and "feeling in love" or feeling "tense" or "frustrated."

- Stress: "A pile-up of life changes"
 - Greater number of stressful events was associated with negative affect a greater proportion of the time.
 - Family stressors showed biggest impact.
 - Depressive mood with family events, Anxious mood with school events
 - Older adolescents showed stronger association between negative affect and stress.
 - Adolescents moving to greater autonomy and influence of peers, and less moderating and predictable effects of the family.

- Cognitive Changes: "Adolescent world is broadening"
 - Adolescence associated with more abstract reasoning, awareness of dynamic social systems.
 - Older adolescents more likely to attribute emotions to events involving peers and romance, abstract concepts, and actual or imagined events outside of the here and now.
 - Younger adolescents attribute negative affect to more concrete and immediate situation.
 - The executive function of "inhibition" develops later in adolescence .

Psychosocial Functioning In Pediatric IBD Mackner et al., 2006

- Healthy Children vs. Children with IBD
 - IBD-greater risk of difficulties with behavioral and emotional functioning.
 - Particularly depression, anxiety, social functioning, selfesteem.
 - Less evidence for family dysfunction, body image, stress and coping, eating problems.
 - Subset of IBD has clinically significant problems.
 - Similar to other children with chronic illnesses.

Psycho-social Challenges of IBD

- Patient Concerns:
 - The unknown causes of IBD
 - Unpredictable course of IBD
 - Embarrassment of bathroom issues
 - Worry about tests and procedures
 - Stress related to medication side-effects, restricted diets, keeping up with complex treatments.

(Cunningham and Banez, 2006)

Psycho-social Challenges of IBD

- Family Concerns:
 - Fear of long-term serious medical problems
 - Fear of child being teased
 - Problems due to growth interference
 - Concern of IBD effect on future parenthood
 - Impact of IBD on entire family including sibs
 - Future insurance problems
 - Concerns over child's emotional ability to deal with IBD

Psycho-social Intervention Guidelines

- Mental health provider should be knowledgeable of physical and emotional experiences of IBD patient.
- Mental health provider should be present throughout the course of treatment.
- Mental health provider should communicate effectively with patient, family and IBD team.
- Mental health provider should normalize reactions to IBD and help parent and family cope.

(Cunningham and Banez, 2006)

Experiential Avoidance (AE) and Cognitive Fusion (CF): The Essence of Human Suffering

Examples of Experiential Avoidance

- Unwillingness to make contact with undesirable, unwanted private mental events, leading to ever widening patterns of behavioral constriction.
- "A Bright Yellow Jeep"

Examples of Cognitive Fusion

• Mistaking private events as "reality." It draws the focus of living away from the present moment into the past and the future.

• "The Virtues of Saliva"

The ACT Model of Human Suffering and Psychopathology

- Human pain (physical and psychological) is ubiquitous, normal and self restorative
- Unwillingness to have pain leads to reliance on avoidance and control based strategies
- Excessive use of control & avoidance leads to a loss of contact with committed actions & vital purposeful living
- It is not physical/mental pain per se that is the "enemy" but our attempts to avoid or control it lead to disorder and suffering
- This cycle of suffering is strongly supported in the culture through language acquisition and socialization

FEAR is in our Mind

- <u>Fusion</u>: excessive attachment to the literal content of thought.
- Evaluation: unhelpful and hurtful evaluations of self, others and the world in general.
- Avoidance: a detrimental style of dealing with private events through avoidance and control.
- Reason Giving: the over use of logical justifications to explain the use of unworkable coping strategies.

The ACT Approach

- The ACT assessment may reveal the following hints:
 - "I am not able to do "A"
 - Behavioral & emotional avoidance
 - "Because there is too much (little) X
 - Cognitive fusion
 - "It is neither normal nor healthy to have this distressing content "X"
 - Evaluation
 - "The presence of this distressing content is a good reason for why I'm not able to do "A"
 - Reason giving, using reasons as causes

The ACT Approach

- The ACT assessment of possible IBD thought(s):
 - I can't do "A" because I have too much "depression/anxiety" or too little "confidence/energy" (experiential avoidance).
 - If only I was more confident or less depressed, then I would be able to do "A" (fusion).
 - Feeling like I do is AWFUL and no one should be expected to do "A" when they have what I have. (example of evaluation relational frame).
 - The "cause" of my depression or low confidence is "IBD". This is an example of reason giving.
 - To improve things, we have to functionally eliminate "IBD."

The Goal of Acceptance and Commitment Therapy (ACT)

• ...is to help patients consistently choose to act effectively (concrete behaviors in alignment with their values) in the presence of difficult or interfering private events. (Strosahl, 2006)

Components of ACT

- Mindfulness
 - Contact with the present moment in a non-judgmental way.
- Acceptance
 - Actively embracing the experience of thoughts, feelings and bodily sensations as they occur.
- Commitment to Values-based living
 - Do what takes you in the direction of your chosen values.

Mindfulness

- Acceptance: being present with self as context
 - Leaves on a stream...
 - Notice experiences in your body
 - Notice how your mind produces thoughts, some random
 - Watch them float by
 - Notice the self that generates the feelings and thoughts

Acceptance: Through Creative Hopelessness

• The cost of choosing avoidance:

•	The (memories, bodily sensations, emotions, thoughts, and
	urges) I most avoid are:

Acceptance: Through Creative Hopelessness

- The cost of choosing avoidance:
 - Avoiding these (memories, bodily sensations, emotions, thoughts, and urges) costs me in the following ways:

- Willingness is:
 - Embracing your pain as you would embrace a crying child.
 - Honoring your pain the way you would honor a friend by listening.
 - Inhaling your pain the way you would take a deep breath.
 - Carrying your pain the way you carry a picture in your wallet.

- Willingness is not:
 - Resisting your pain.
 - Ignoring or forgetting your pain.
 - Doing what pain says.
 - Not doing what pain says.
 - Believing your pain.
 - Not believing your pain.
- Willingness is the answer "yes" to the question "Will you take me as I am?"

• "What would you have to accept to move your life toward what you value?"

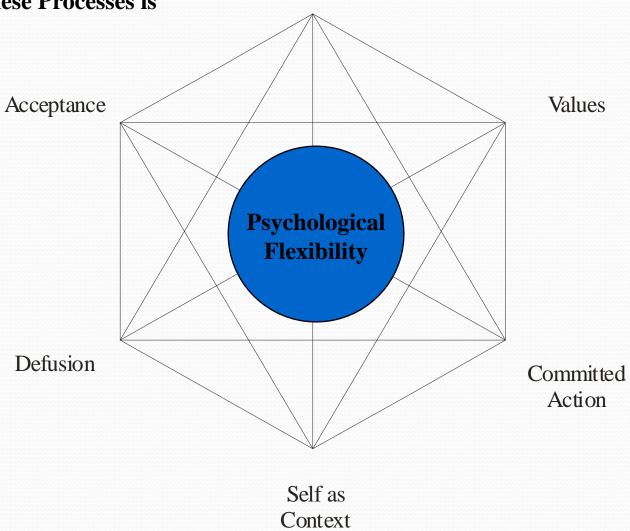
• "Focus on what you can control and change (your actions) and accept what you can't."

- Values: the process of going in a meaningful direction. It is not an object or goal to be achieved. Values are timeless and guide chosen actions in a person's life.
 - Example: One of my values is to be a loving person. Are you finished after a few days of being loving? Is it like earning a diploma?



Contact with the Present Moment

All of These Processes is



ACT

- A ccept- unwanted private experiences
- C hoose- a set of valued life directions
- T ake action-build larger patterns of meaningful actions that are consistent with values

