PSYCHOLOGICAL ASPECTS OF IBD

ADDRESSING THE COMPLEXITIES OF A CHRONIC DISEASE

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Objectives

• Review IBD complexities
• Role of mood and IBD
• Behavioral health treatment options
• Coping strategies
• How to take action
Disease Complexities

- Disease specific knowledge
- Medication hx
- Personal disease hx
- Importance of preventative health
- Disease activity and reproductive health
- Effect of diet, smoking, NSAID use

- Navigate the health system
- Access preventative health services
- Interpret test results
- Communicate with Drs
- Mindfully consume health-related information

Medical Knowledge

Health Literacy

Self-Management

Self-Efficacy

- Recognition of disease flare
- Treatment adherence
- Smoking cessation
- Ostomy care
- Medication re-fills
- Scheduling clinic visits

- Belief that you have the ability to organize and execute behaviors necessary to manage challenging situations

Trivedi I & Keefer L Gastroenterol Res Pract. 2015
Living with an invisible illness

- Experimental medications
- Hospital stays
- PREDNISONE
- Chronic pain
- Insomnia
- Food restrictions
- Medical bills
- Missed events
- Career impacts
- Relationship challenges
- Pregnancy
- Fear of the future
- Ostomy
Question 1

I am actively working with a mental health provider to help me manage the complexities of having IBD.

True

False
Lifetime Incidence of Anxiety and Depression in IBD

Association of Mood Disorders and Course of IBD

- Patients with active or fluctuating IBD have
  - Lower quality of life
  - More stress
  - More health anxiety and pain anxiety
  - Feeling of little control of their lives
  - Need for more potent medication
  - Are more likely to have maladaptive coping skills
    - Avoidant coping

Graff, et al. AJG 2009
Lix, et al. IBD 2008
Identify how you feel

- Isolated
- Stressed
- Embarrassed
- Sad
- Depressed
- Anxious
- Helpless
- Frustrated
- Overwhelmed
- Guilty
- Angry

It’s important to understand that these feelings are perfectly normal.

The better you can manage your IBD symptoms, the better you’ll be able to cope with these feelings.
How does IBD impact your relationships?

“I’ve distanced myself from family or friends because they don’t seem to understand this disease.”

“I find myself avoiding coworkers, and even social and professional opportunities at work or school.”

“Now we have to plan to be intimate.”

“There is a lot of guilt around missing family activities.”

“My family doesn’t always know how to support me and at times we all feel helpless.”

“Sometimes the pain and frustration of IBD is overwhelming, and I take it out on my loved ones.”
The Other Side

“IBD has made my relationships stronger!”

“I have learned how to communicate more clearly what my needs are and how my loved ones can support me.”

“Without IBD, I wouldn’t have met certain people who have changed my life for the better.”

“I sweat the small stuff less and have more appreciation for things that can be easily taken for granted.”
Question 2

How many people have or have had an ostomy?
   1) I currently have an ostomy
   2) I have had an ostomy
   3) I am currently contemplating an ostomy
Ostomy

• An **ostomy** is a surgically made *opening into* the body.
  - A passageway made by a surgeon through the abdominal wall to serve as an exit for body waste.
  - A **stoma** is the new opening on the abdomen.

• Best estimates indicate ~500,000 people in the US and Canada currently have an ostomy.

• Each year there are ~120,000 new ostomy surgeries.

• Ostomate is the common term for someone who has an ostomy.

From: The Ostomy Book By Mullen & McGinn
## Complexities of an Ostomy

<table>
<thead>
<tr>
<th>Before</th>
<th>After</th>
<th>Future</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor visits</td>
<td>Acclimating to a Front Butt</td>
<td>Unknowns</td>
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<tr>
<td>Failed treatments</td>
<td>Leaks</td>
<td>Uncontrollables</td>
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<td>Colonoscopies and other tests</td>
<td>Learning how to close the bag correctly</td>
<td>Re-entering the world</td>
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<tr>
<td>Worsening symptoms</td>
<td>Diet</td>
<td>Sex and Intimacy</td>
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<td>Best friend = toilet</td>
<td>How to dress</td>
<td>Adjusting to your body</td>
</tr>
<tr>
<td>Missed work or school</td>
<td>Educating others</td>
<td>3D printed customized ostomy wafers</td>
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<tr>
<td>Life passing by</td>
<td>Learning how to travel</td>
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<tr>
<td></td>
<td>Pets or people ripping off bag in your sleep</td>
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</tr>
</tbody>
</table>
The Ostomate Bill of Rights

The Ostomate shall:

1) Be given pre-op counseling.
2) Have an appropriately positioned stoma site.
3) Have a well constructed stoma.
4) Have skilled post-operative nursing care.
5) Have emotional support.
6) Have individual instruction.
7) Be informed on the availability of supplies.
8) Be provided with information on community resources.
9) Have a post-hospital follow-up.
10) Benefit from team efforts of health-care professionals.
11) Be provided with information and counsel from the ostomy association and its members.

From: The Ostomy Book By Mullen & McGinn (p. 50)
"Acceptance doesn't mean resignation. It means understanding that something is what it is and there's got to be a way through it"

- Michael J. Fox
Initial GI discomfort (abdominal pain, diarrhea)

Unhelpful Thoughts (“Oh no, I’m going to have an accident…”)

Emotions (anxious, embarrassed, angry)

Sympathetic Arousal (HR, respiration, GI distress)

worsening GI symptoms

GI Health Psychologist
Us of Adaptive Coping Skills

- Plan
- Approach
- Organize
- Emphasis resolution
- Take action

- Acceptance
- Utilize social support
- Relaxation
- Constructive self talk
- Adopt a “so what” approach
- Let it GO
LOOK, I DON'T KNOW WHY THE SQUARE PEG DOESN'T FIT IN THE ROUND HOLE

BUT THAT'S NOT MY PROBLEM. FIX IT.
Find yourself in the present moment, use your senses, notice the colors around you, exercise, meditate, body scan.

Talk with a loved one, listen to music, clean, make a list, TV, social media, learn something new, craft, games.

Ugly cry, scream, yell, cold shower, put on funny DVD & make yourself laugh, dance crazy, try boxing, sing.

Favorite meal, mani/pedi, bubble bath, get hair done, buy a small treat, massage, cuddle with a pet...or partner.

“Is this thinking helpful?” What advice would you give a friend?
Pros verse Cons of your thinking.

Smile at a stranger, volunteer, pray, meditate, RA K, join a cause, help someone else, write a letter, gratitude.

Adapted from resources at www.indigodaya.com
The Role of Exercise

- Barriers: unpredictable nature, pain, fatigue, fear of fecal incontinence
- Moderate exercise does not appear to have negative health effects and may diminish some symptoms of IBD.
- Exercise may offset some IBD specific complications such by improving:
  - Immunological response
  - Psychological health/Quality of life
  - Strength
  - Fatigue
  - Nutritional status
  - Bone mineral density
  - Reversing the decrease of muscle mass

- Be prepared to adjust your activity level based on how you are feeling

Nathan I et al. Gastroenterol Nurs 2013
# Web-based Resources

## Table 1: Online resources for patients with ulcerative colitis or Crohn’s disease

<table>
<thead>
<tr>
<th>Site</th>
<th>Web-based intervention</th>
<th>Disease information</th>
<th>Medication/treatment information</th>
<th>Support group</th>
<th>Discussion group(s)</th>
<th>Links to other resources</th>
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Abbreviation: CCFA, Crohn’s and Colitis Foundation of America.
Self Efficacy – Taking Care of You

• Talk to your doctor about a treatment plan that helps you better manage your IBD symptoms
• Educate your family and friends about IBD so they better understand what you are going through and how to support you
• Seek support from a therapist who knows about IBD
• Join a local support group
• Join the CCFA Community
• Become an advocate for yourself and others living with IBD
Resources

• *I’ll Be Determined* website, *Quality of Life Journey*: http://www.ibdetermined.org/Journeys-QOL.aspx

• *CCFA Community* website: www.ccfacommunity.org

• *Emotional Factors* fact sheet: http://www.ccfa.org/assets/pdfs/emotional.pdf

Ostomy Resources

- United Ostomy Association of America (UOAA)
  - www.uoaa.org (discussion board)
  - www.ostomy.org (everything else)
- International Association for Medical Assistance to Travelers
  - www.iamat.org or 1-716-754-4883
- Shaz’s Ostomy Pages for discussions on pregnancy
  - www.ostomates.org/pregnancy.html
- The Ostomy Book: Living Comfortably with Colostomies, Ileostomies, and Urostomies
  - By: Barbara Dorr Mullen and Kerry Ann McGinn, RN, ARNP
- It’s In The Bag and Under The Covers: Stories of Dating, Intimacy, Sex, & Caregiving About People with Ostomies
  - By: Brenda Elsagher