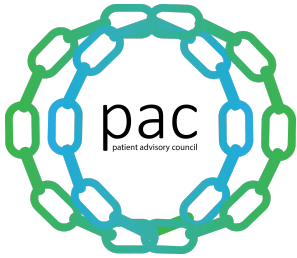


Patient Advisory Council

Disordered Eating Toolkit

A resource created by members of the Patient Advisory Council of ImproveCareNow. The purpose of this resource is to spark discussion about disordered eating behavior in IBD patients and the significant impact it can have in a patient's life. This resource includes patient and expert experience with disordered eating.





Disclaimer

This document was created by members of the ImproveCareNow Community. Do not rely on the information in this document to diagnose or treat any health condition. This information does not constitute medical advice and is not intended to be a substitute for professional medical advice, diagnosis, or treatment.

Disclaimers posted at
http://www.improvecarenow.org/icn_tools_disclaimer
apply to this document.

About the PAC

The Patient Advisory Council (PAC), is a community of young (14+) patients with Inflammatory Bowel Disease (IBD) who come together to give and receive support, ask questions, share information, and network with each other. For more information about the PAC, [click here](#).



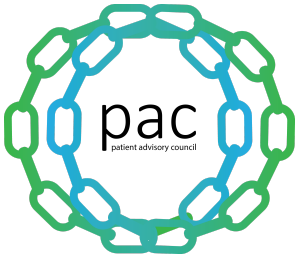


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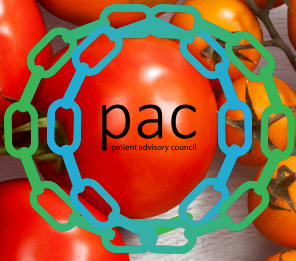
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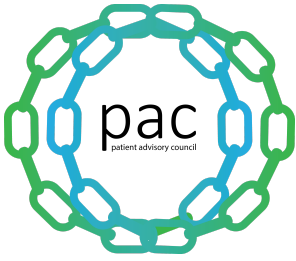




Introduction to Disordered Eating

Insights on disordered eating
from an expert's perspective





Thoughts, feelings, and behaviors related to eating



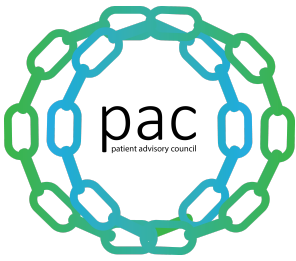
Every person, with or without IBD, has thoughts, feelings, and behaviors related to eating.

For example, you may think, “**This is going to taste bad!**” when you see kale. You may get very **excited when you get your favorite food**. Or, perhaps you **try very hard to eat a variety of foods** across all of the food groups.

For everyone, thoughts, feelings, and behaviors related to eating can ***change over time***.

This is normal.

This resource is focused on circumstances when these thoughts, feelings, and behaviors impact medical and psychosocial health.



Healthy vs Disordered Eating Habits

Healthy eating habits: consuming recommended calories and foods/food groups and only restricting calories/foods as medically indicated.

Examples of healthy eating habits

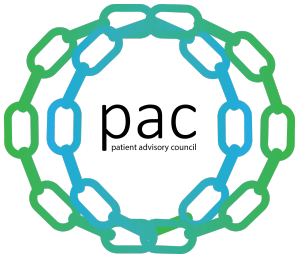
- Feeling **empowered** and **involved** when choosing snacks and meals
- **Enjoying eating** without worries about calories
- Choosing and restricting foods that are **consistent with medical recommendations**, such as complying with prescribed dietary restrictions, and eating a balanced diet



Disordered eating habits: problematic thoughts and/or behaviors related to food, weight, or shape, in the context of living with IBD

Examples of disordered eating habits

- **Excessive restriction** of foods while on specific medications when not indicated by a medical provider
- Significant concern using treatments may involve changes to **foods**, **weight**, or **body appearance**
- Avoidance and/or distress when discussing **weight** or **being weighed**
- Poor adherence to medications/treatments in order to alter **weight** or **physical appearance**



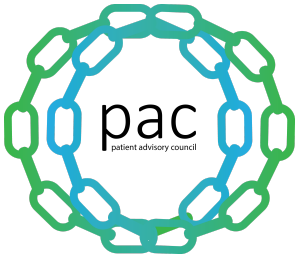
What is the difference between disordered eating and a diagnosable eating disorder?

Disordered Eating

- Includes unhealthy thoughts and behaviors related to eating, such as lots of worries about one's weight or restricting caloric intake
- Does not significantly impact the individual's functioning, but may still have a negative impact on the individual's life

Eating Disorder

- Includes thoughts and behaviors requiring significant time and energy spent on restricting calories, thinking about food, and ruminating over body image, shape, and weight.
- Has a clinically significant impact on an individual's functioning and interferes with the individual's daily life, e.g., school, work, or social functioning



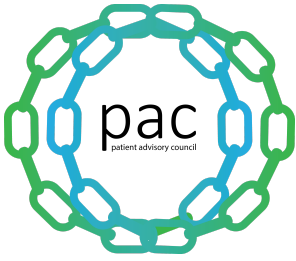
How Prevalent is Disordered Eating in IBD?

In a pilot study¹ of adolescents with IBD, about **30%** reported clinically significant shape concerns (i.e., discomfort with body shape).

Almost **20%** reported clinically significant disordered eating.

The prevalence of disordered eating and body image concerns remain an **important and under-studied** research question in pediatric IBD.

¹ David, J., Daly, B., Reed, B., Saeed, S., Atay, O., DeMatteo, D., & Chute, D. (2020). Assessing the prevalence of and risk factors for disordered eating behaviors in adolescents with Inflammatory Bowel Disease. Poster presentation at the Society of Pediatric Psychology Annual Conference, Dallas, TX.



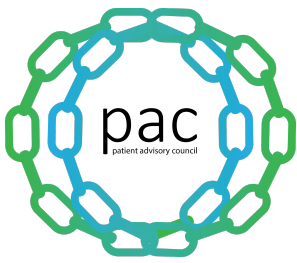
Common Misconceptions about Disordered Eating & IBD

Misconception: Only female patients have disordered eating thoughts and behaviors.

Truth: Both male and female patients can develop disordered eating thoughts and behaviors.

Misconception: Disordered eating is only restricting calories.

Truth: Disordered eating thoughts and behaviors can present in many different ways, including binge eating, anxiety around food, weight, or body shape, excessive physical exercise and body image difficulties.



The Psychosocial and Medical Impacts of Disordered Eating in IBD Patients

Disordered eating continues to be an **important** and **understudied** area of research in pediatric IBD. Early research suggests that disordered eating is associated with body image concerns, poor health-related quality of life, anxiety, and depression¹.

Disordered eating in pediatric IBD may look **different** across the developmental span, but remains an **important consideration for all children and adolescents with IBD**.

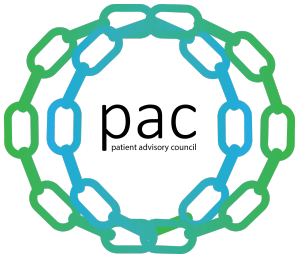
Disordered eating habits: problematic thoughts and/or behaviors related to food, weight, or shape, in the context of living with IBD

Examples of disordered eating habits

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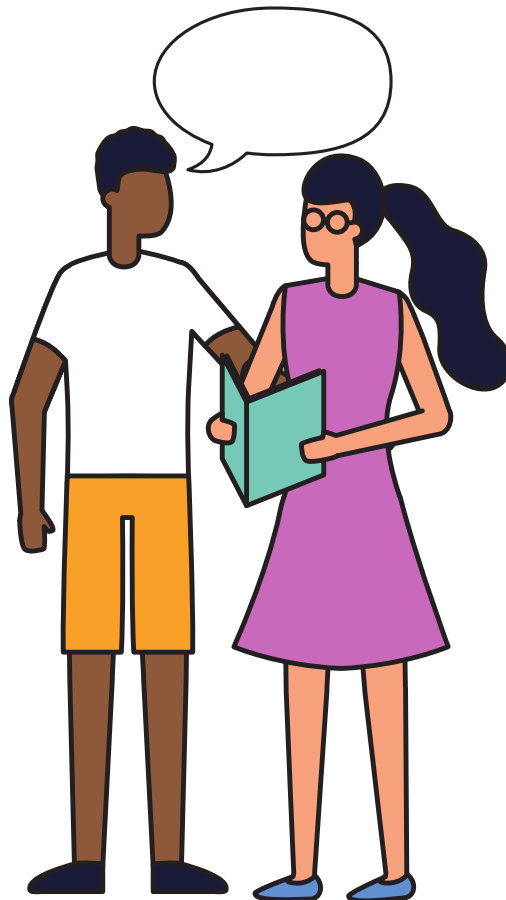


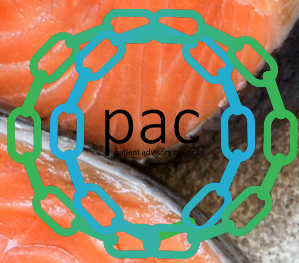
¹ David, J., Daly, B., Reed, B., Saeed, S., Atay, O., DeMatteo, D., & Chute, D. (2020). Assessing the prevalence of and risk factors for disordered eating behaviors in adolescents with Inflammatory Bowel Disease. Poster presentation at the Society of Pediatric Psychology Annual Conference, Dallas, TX.



What are some things IBD patients can do to address disordered eating thoughts and/or behaviors?

- Talk to your family and friends
- Reach out to your medical provider to connect you to the resources you need
- Work with a psychologist trained in evidence-based approaches for managing disordered eating behaviors

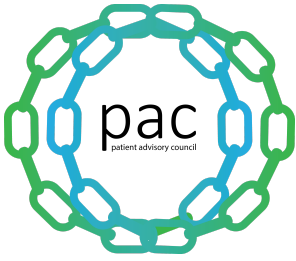




Patient Perspectives

Disordered Eating Related to IBD Symptoms

Disclaimer: Some of the experiences shared would NOT be classified as disordered eating



Patient Experiences with Disordered Eating

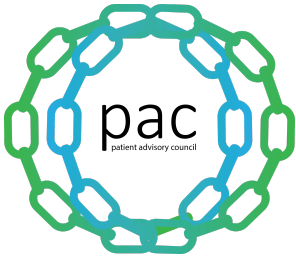
Question: What IBD experiences impact your eating thoughts and behaviors?

Answers:

- Abdominal pain, indigestion, nausea, bloating, bowel urgency, and incontinence
- Physical limitations, including fatigue and weakness
- IBD-related changes to diet, weight, physical appearance
- IBD treatment-related factors, such as enteral feeding, steroids, or surgery
- The potential psychosocial challenges of living with a chronic illness

Disordered eating thoughts and behaviors **may look different** from patient to patient. It is important to make space for every story and experience.





Patient Experiences with Disordered Eating

Question: What foods do you restrict or consume more of because of symptoms?

Answers:

- **Commonly restricted foods:** red meat, raw vegetables, sweets, nuts, and seeds.
- **Common safe foods:** low fiber diet, cooked fruits and vegetables, and eggs.

Question: How do your eating behaviors change when you don't feel well?

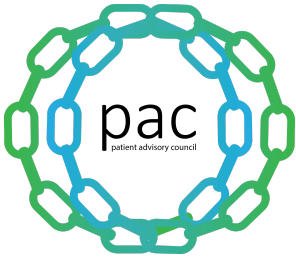
Answers:

"I avoid foods that may cause symptoms and make me even less likely to engage in physical activity. I am also more prone to eat less in fear of overeating on days I am fatigued or unable to participate in my regular exercise routine."

Maddie

"If I'm feeling low energy, it's difficult for me to grocery shop, make myself food, and clean up. This means I will sometimes stick with easier foods that require little preparation, which aren't always the healthiest options. I tend to snack rather than eat full meals, so my caloric intake can be pretty variable depending on how I'm feeling that day."

Rosa

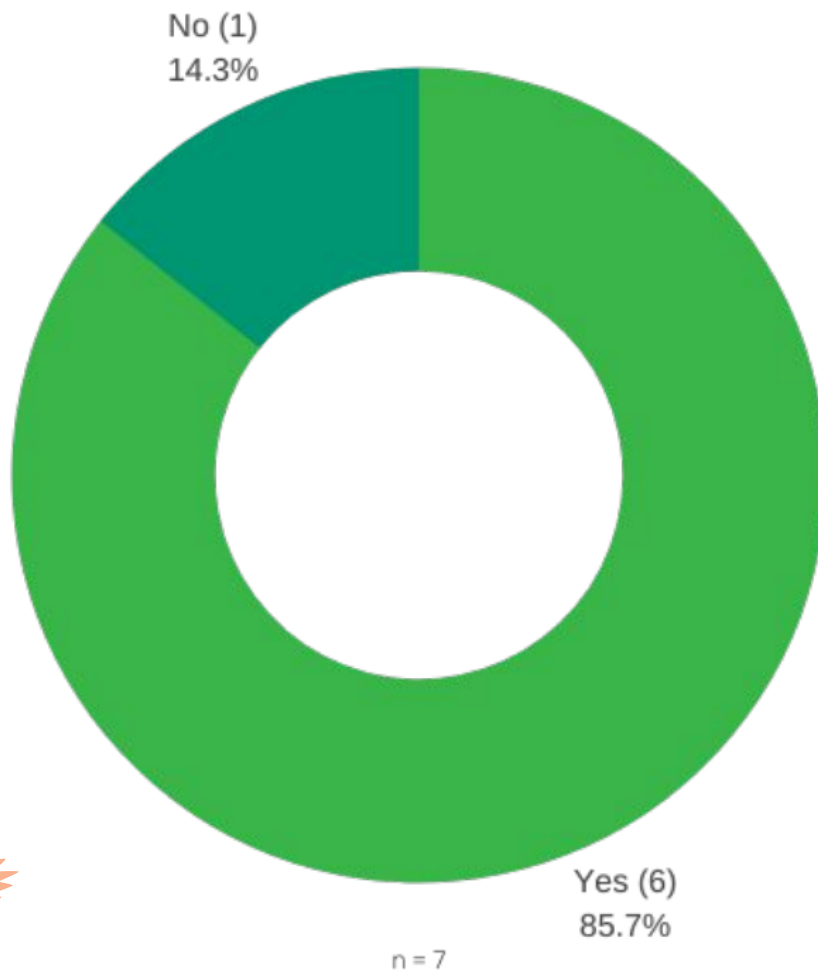


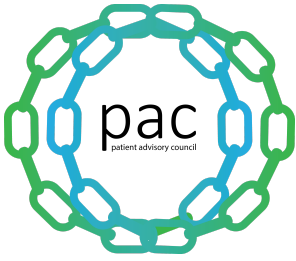
Patient Experiences with Disordered Eating

Question: Has IBD-related weight change impacted your eating behaviors?

Answers:

Data from PAC member survey





Patient Experiences with Disordered Eating

Question: How do you alter your eating behaviors to compensate for IBD-related weight changes?

Answers:

"If I've lost weight due to my IBD, I try to eat more calorically dense foods - though this can be difficult because I don't digest these things well!"

Rosa

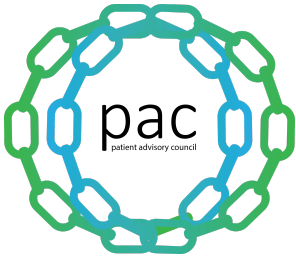
"When I couldn't absorb much nutrients and I wasn't growing, I tried eating more and better. Once I was put on prednisone, I was eating too much and had to catch myself binging."

Brady

"I can't really do much because the low fiber diet causes me to gain weight and I've been sedentary for two years because of chronic tailbone pain."

Gabi





Answers (cont.):

"I eat high calorie foods or decrease fiber."

Nour

"I lost so much weight during my first flare/diagnosis, my body tried to compensate for the weight lost and eat more than necessary."

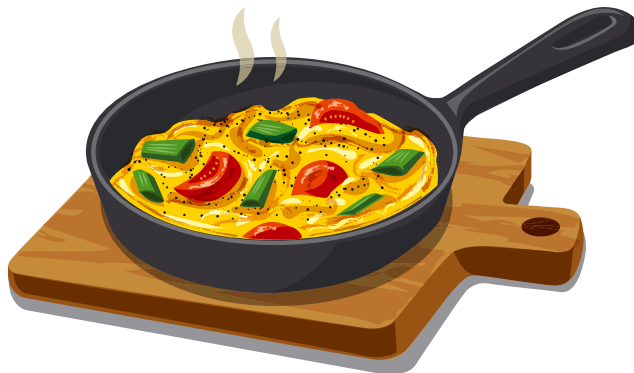
Linden

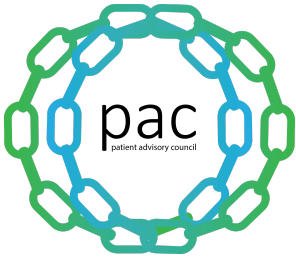
"I added a nutritional therapy and consumed a diet that is mostly liquid."

Natalie

"When I lost weight due to malnutrition, I compensated by consuming excess calories during the day."

Maddie



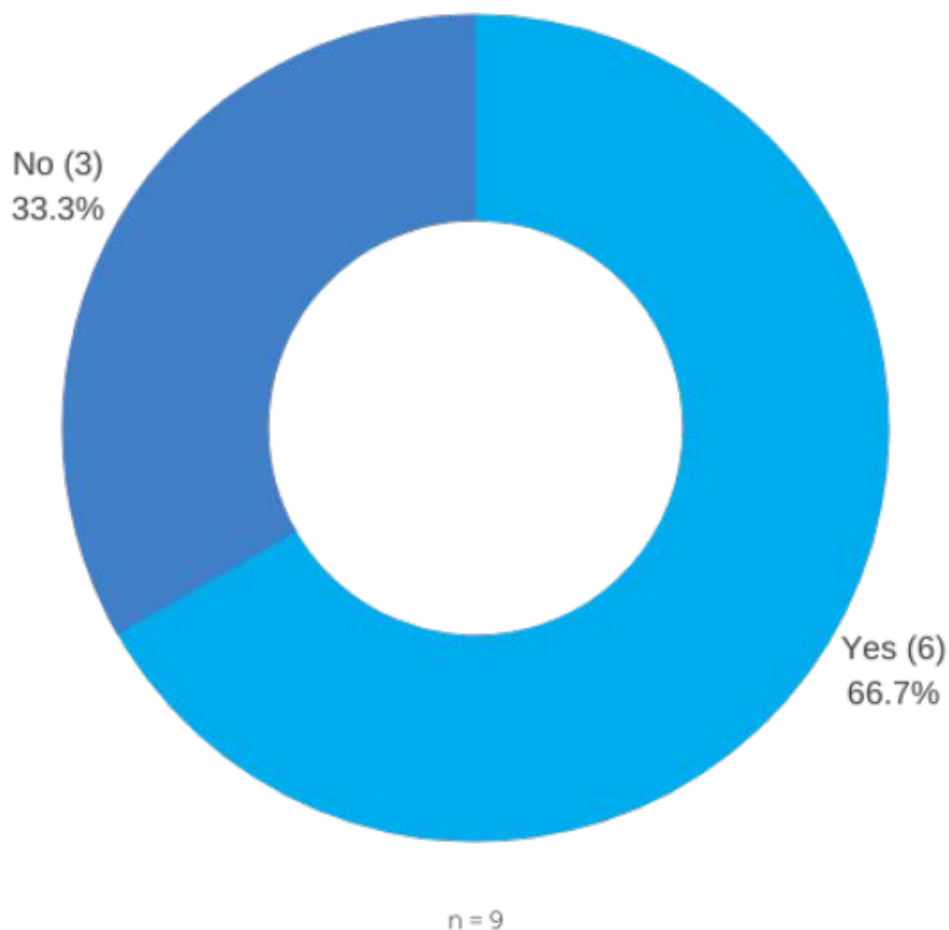


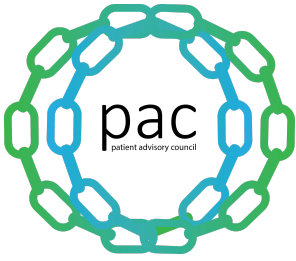
Patient Experiences with Disordered Eating

Question: Does your self-esteem related to your IBD impact your eating behaviors?

Answers:

Data from PAC member survey





Patient Experiences with Disordered Eating

Question: What IBD-related concerns impact your eating behaviors?

Answers:

- Concerns about appearing “**too thin**” or “**ill**”
- Concerns about **weight gain or loss**
- Fear of **sudden changes** in weight
- Concern that eating will lead to **inflammation**
- Fear that eating will cause disease **symptoms**

Question: How do these symptoms impact your eating behaviors?

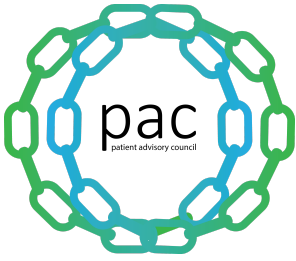
Answers:

“My IBD hasn’t affected my eating habits. I’m proud of how strong I am and how I’ve overcome the difficulties.”

Gabi

“Since I was used to being small partially due to IBD, growing and putting on weight during puberty was a little difficult to accept and uncomfortable. It was great that I finally grew, but the sudden change and wanting to feel in control of my IBD and body affected my eating habits. I would eat more or less to feel in control.”

Fionna



Question: What IBD-related concerns impact your eating behaviors?

Answers (cont.):

"I eat foods that prevent me from bloating."

Nour

"I attempt to compensate for fluctuations in my weight by eating more or less to feel in control of my body."

"I restrict foods that can trigger my symptoms."

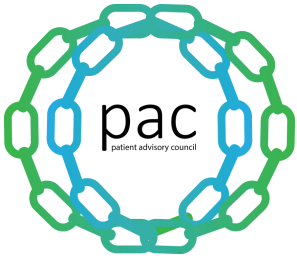
Natalie

Maddie

"When I can tell I've lost weight, I try to make myself eat more than I normally would. In the past, this behavior has bordered on obsessive eating, so I try not to count calories now."

Rosa



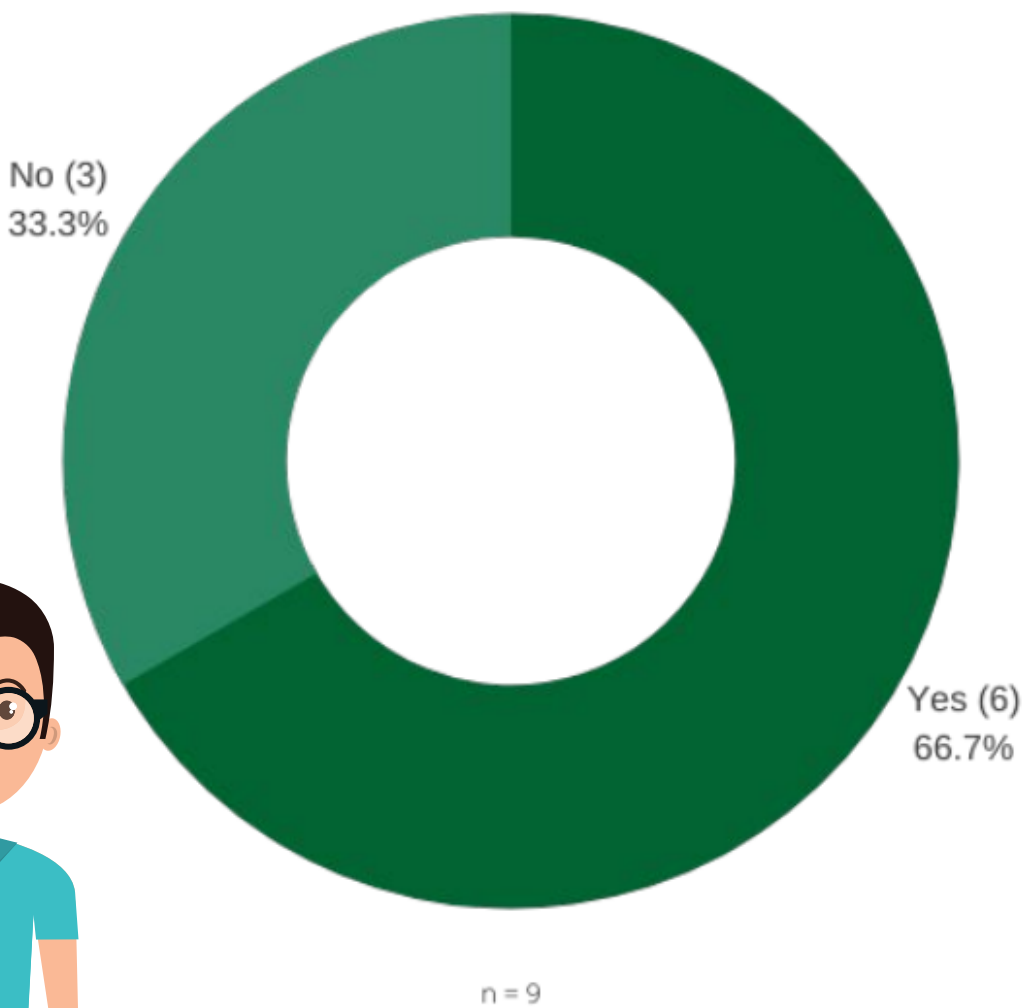


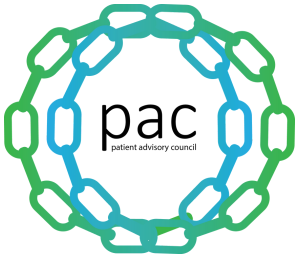
Patient Experiences with Disordered Eating

Question: Are your eating behaviors impacted by a desire for control?

Answers:

Data from PAC member survey





Patient Experiences with Disordered Eating

Question: How do worries about control impact your eating behaviors?

Answers:

"I try to eat better to feel like I am gaining more control."

Brady

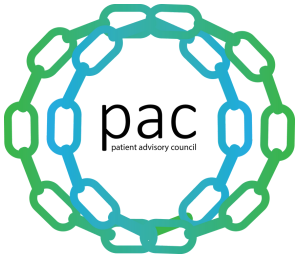
"I will avoid foods that I have eaten before throwing up, even if it was probably not the cause. I am also hesitant to try new foods if I don't know how they'll make me feel."

Fionna

"When I was stressed (even not about IBD), it was sometimes my natural instinct to restrict food. It took me a few years and a wonderful counselor to help me through this and realizing eating is a form of self-care as long as it's thoughtful and celebrated- but my GI doctor had no idea."

Sami





Patient Experiences with Disordered Eating

Question: How do worries about control impact your eating behaviors?

Answers (cont.):

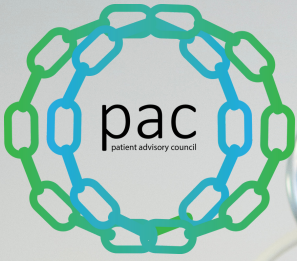
"I eat less for fear of overeating and making myself sick. I sometimes feel that it is better to be hungry but somewhat in control of my body than to eat and feel out of control with my symptoms. I want to be in control of my weight. In the past, I have tracked my calories or restricted my food intake just to feel that my weight was in my control."

Maddie

"I was on very restrictive diets to control symptoms, and since many of the foods I could eat weren't very calorie dense, I had to eat essentially all day to get adequate nutritional intake."

Rosa

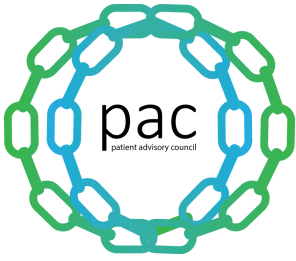




Patient Perspectives

Disordered Eating Related to IBD Treatment

Disclaimer: Some of the experiences shared may NOT be classified as disordered eating.



Patient Experiences with Disordered Eating

Question: What therapies have impacted your eating behaviors?

Answers:

- Exclusive Enteral Nutrition
- Restrictive diets
- NG Tube feedings
- Steroids



Question: How do you modify your eating behaviors because of your experiences with IBD therapies?

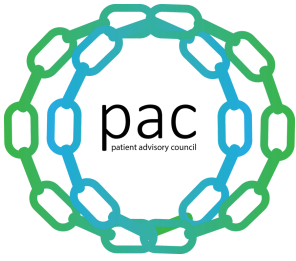
Answers:

"Sometimes I will overeat/eat when I don't feel particularly hungry in an effort to gain weight and intake more calories. I also will drink more formula if I'm not feeling great that day instead of eating more food, which is not bad but it doesn't feel good psychologically because I would much rather be eating real people food. Being on SCD has also changed my eating habits as I have become more obsessed with calorie counting than intuitive eating, which can trigger anxiety sometimes."

Maha

"I try to stop myself bingeing snack foods or just too much food in general when on the medicine [Prednisone]."

Brady



Patient Experiences with Disordered Eating

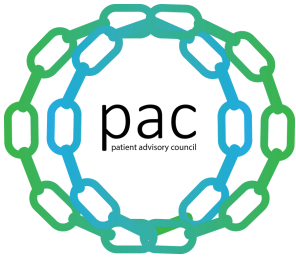
Question: How do you modify your eating behaviors because of your experiences with IBD therapies?

Answers (cont.):

“When I was on steroids, my eating habits changed a lot. I was constantly hungry, and would binge-eat snack food. I actually kept food by my bed when I went to sleep, because the hunger would wake me up in the night! Being on therapeutic diets also really modified my eating habits - similar to when I was on steroids, I was hungry all the time, but this was because my diet was so limited. I could mainly eat meat and cooked veggies, which never made me feel fully satisfied. I felt like I needed to constantly be around 'safe' food in case I got hungry, which restricted what I was able to do socially.”

Rosa





Patient Experiences with Disordered Eating

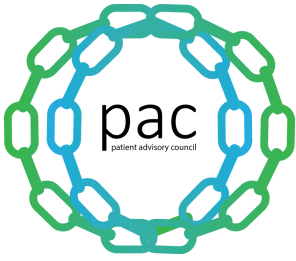
Question: How do you modify your eating behaviors because of your experiences with IBD therapies?

Answers (cont.):

"I sometimes eat more than is enjoyable because of my experiences with EEN and tube feeding. I have an impulse to eat food in front of me simply because I am able to. I have to remind myself that overeating will not be enjoyable later, however amazing the food tastes in the moment. My experience with restrictive diets has made me more prone to overeat on new or exciting meals. This is because of the somewhat infrequency of new and exciting foods I am allowed to consume. I have to be aware to not overeat. New tastes and food experiences are so wonderful in the world of restrictive diets and not consuming too much of those foods is difficult. With regards to EEN, I sometimes restrict my food intake out of a fear of weight gain because I put on significant weight while on that therapy."

Maddie





Patient Experiences with Disordered Eating

Question: What treatment related fears do you experience related to disordered eating?

Answers:

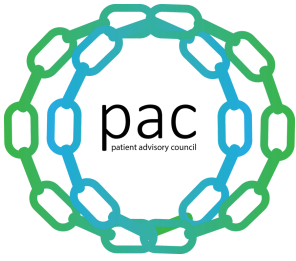
- Fear of food being **taken away** or **unavailable**
- Fear of **binge eating** and not being able to stop
- Fear of food **making IBD worse**
- Fear of eating and **feeling sick** afterward
- Fear of **gaining or losing weight**
- Fear of **appearance after eating**

Question: Explain a time where your experience with IBD treatment impacted eating behaviors.

Answers:

“When I was on steroids, I tried to eat very low sodium because I heard it can help with water retention and prednisone “moon face.” I became pretty obsessed with keeping my sodium intake low, and wouldn't eat anything that had over a certain amount of sodium in it. This ended up being a bad idea - it turns out I was eating way too little sodium, and ended up feeling very dizzy and sick.”

Rosa



Patient Experiences with Disordered Eating

Question: Explain a time where your experience with IBD treatment impacted eating behaviors.

Answers (cont.):

"I was in LA on my first solo trip since diagnosis. I was in LA for a choir competition and I was so scared of not hitting my calorie count and getting sick that I accidentally overdid my calories and ended up throwing up that night because I overcompensated. It reflects how my mindset has become more about calorie goals rather than intuitive eating."

Maha

"After transitioning from EEN and tube feeds to solid food, there was a time when I consumed far too much a dessert out of an excitement to eat again. The dessert was compliant with my regular dietary restrictions, but the incredible amount I ate in one sitting was enough to make me sick for the next several days."

Maddie

"For the time that I was on Prednisone, I would eat way more than I normally would, and every time I would eat a lot in one sitting I would feel bloated, yet still be hungry."

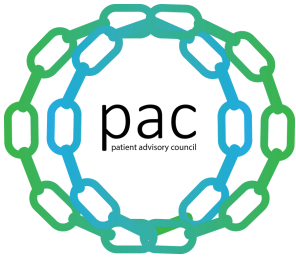
Brady



Patient Perspectives

Day-to-Day with IBD and
Disordered Eating Behaviors





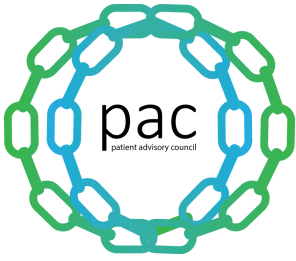
Patient Experiences with Disordered Eating

Question: How would you suggest parents/providers promote healthy discussion about disordered eating in IBD patients?

Answers:

- Identify **triggers**
- Avoid **weight** language
- Involve a **nutritionist** or **dietitian** in the conversation
- Create a **safe** space to talk
- Promote foods the patient finds **nourishing** and **comforting**
- Promote activities that help the patient **feel alive in their body** (e.g., meditation, exercise)
- Approach the conversation with **empathy** for the patient
- Involve a **psychologist** or **mental health professional**





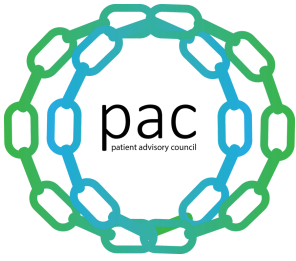
Patient Experiences with Disordered Eating

Question: What has been a successful strategy for you to manage disordered eating related to your IBD?

Answers:

- Asking, “**Am I actually hungry?**”
- Taking care of both **physical** and **emotional** health
- Practicing **moderate exercise**
- Practicing **self-compassion**





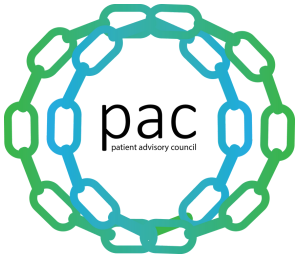
Patient Experiences with Disordered Eating

Question: What has NOT been a successful strategy for you to manage disordered eating related to your IBD?

Answers:

- The phrases, "**You look too skinny,**" "**you should eat more,**" or "**you don't look underweight! You should eat less.**"
- Oversimplifying disordered eating and naming it as only **anxiety** or **depression**
- Generalizing eating patterns to be a result of **gluttony** or **laziness**





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