



Life Disrupted: Role of Advanced Practice Providers in Guiding Patients with Crohn's Disease Through the Challenges of Bowel Urgency

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Learning Objective 1

Identify the contributions of bowel urgency, fatigue, psychosocial symptoms, and histologic/endoscopic healing in the burden of CD and their effects on patient QoL

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Learning Objective **2**

Evaluate bowel urgency, fatigue, psychosocial symptoms, and histologic/endoscopic healing for patients with CD as part of thorough symptom evaluation

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Learning
Objective **3**

Engage patients in open communication about their bowel urgency, fatigue, psychosocial symptoms, and histologic/endoscopic healing with the goal of improving clinical outcomes

Audience Response

How often do you incorporate bowel urgency assessments into your evaluation of patients with Crohn's disease (CD)?

- A. 0% of the time
- B. 1-25% of the time
- C. 26-50% of the time
- D. 51-75% of the time
- E. 76-100% of the time

CD Symptoms Start Long Before Diagnosis

Symptom onset



First health care contact



Specialist review



IBD diagnosis

Total time to IBD diagnosis



8 months is median time to diagnosis in CD



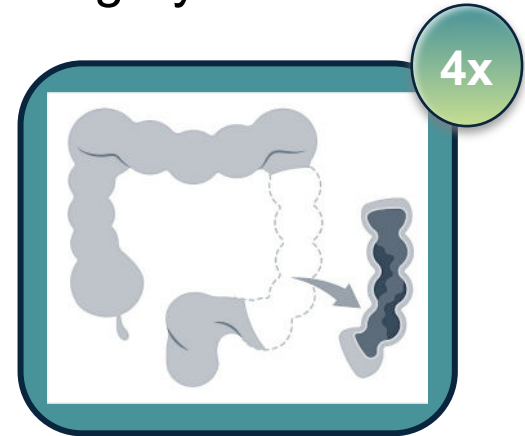
1 in 10 patients have symptoms duration of 5 years before diagnosis

Delayed Diagnosis Increases Risk of IBD-Related Complications



Delayed diagnosis of CD associated with a higher likelihood of stricturing and penetrating disease and 2-fold increase in the need for surgery

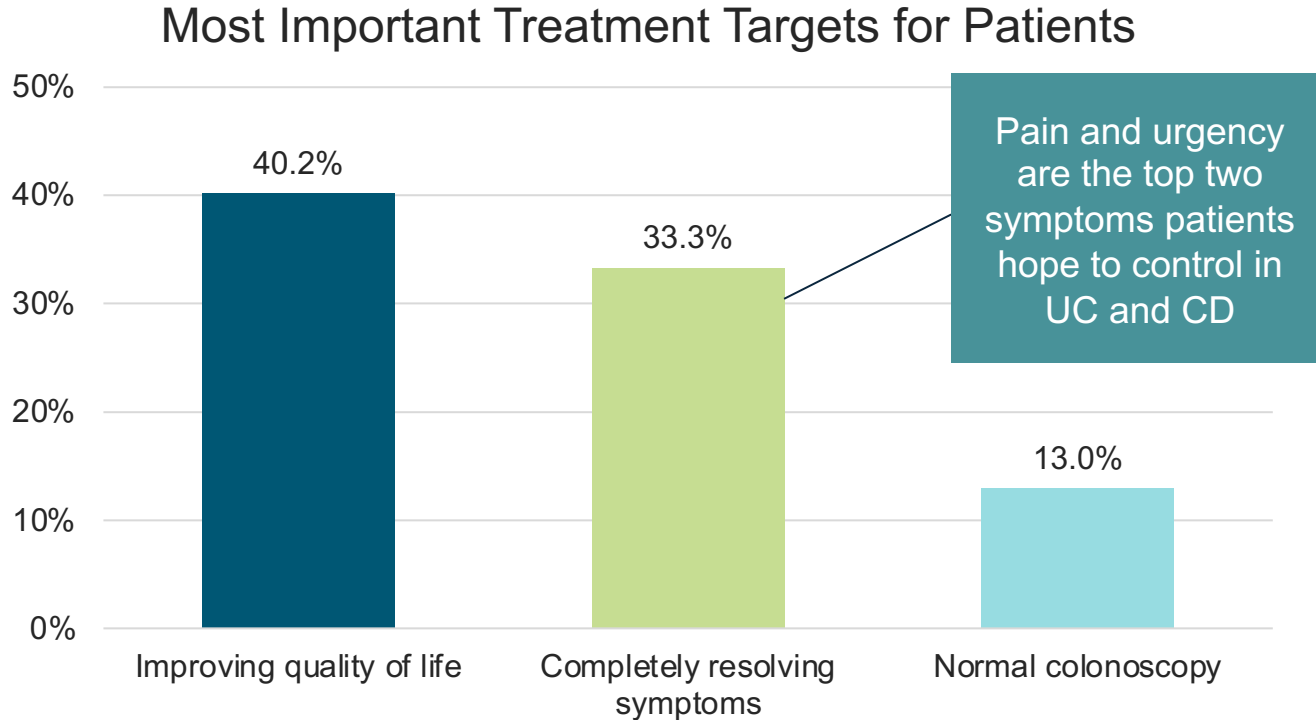
Delayed diagnosis of UC associated with 4-fold increase in the need for colectomy



UC = ulcerative colitis

Jayasooriya N, et al. *Aliment Pharmacol Ther.* 2023;57(6):635-652.

Patients with CD Most Want Pain and Urgency to Improve with Treatment



Bowel Urgency Can Lead to Incontinence

Urgency

Feeling the need
to rush to the
bathroom

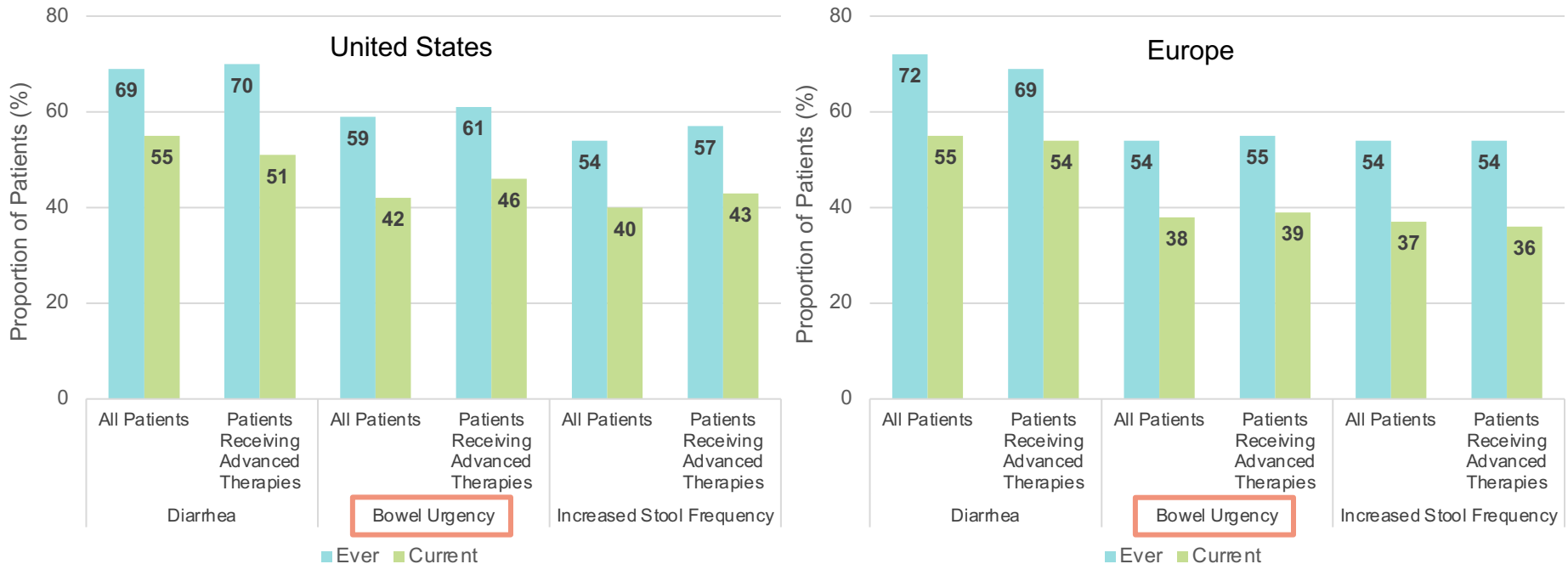


Incontinence

Loss of
bowel control

CONFIDE Survey Results

Bowel urgency was among the top three most frequently reported CD symptoms



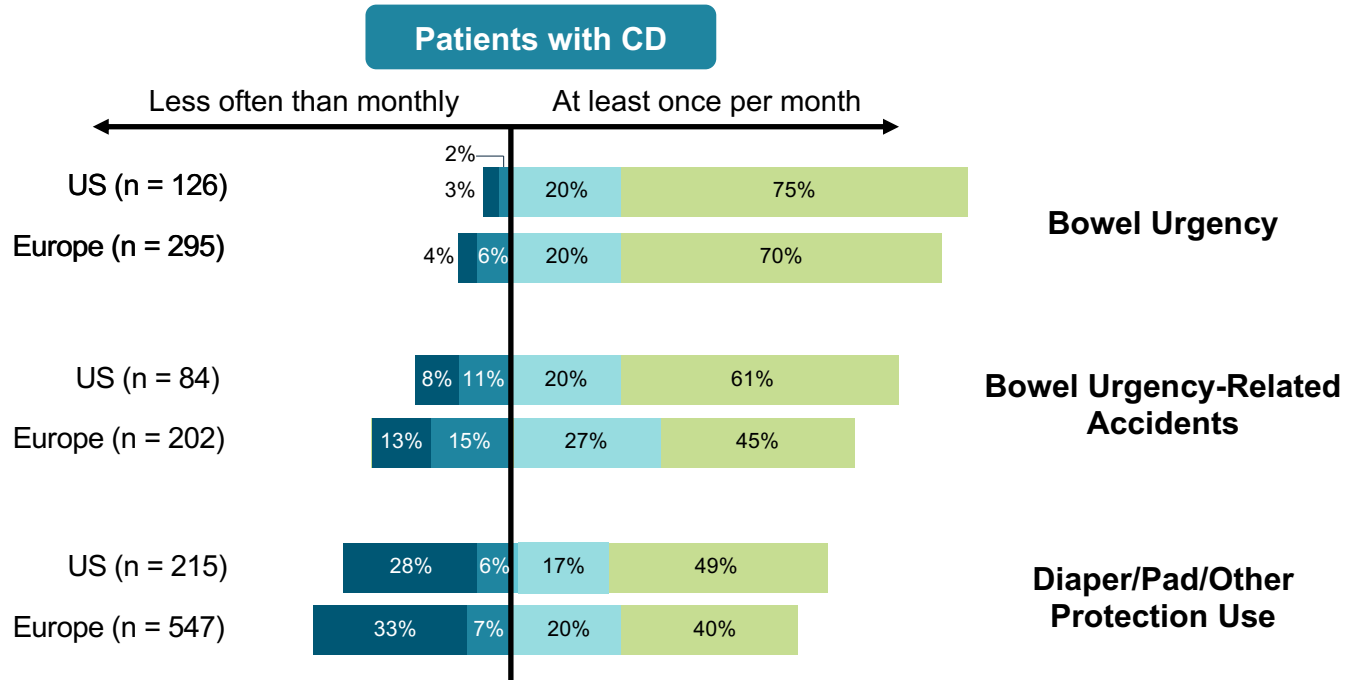
CONFIDE = Communicating Needs and Features of IBD Experiences

Schreiber S, Gibble TH, Dubinsky MC, et al. *Am J Gastroenterol.* 2023;118(10S):S815.

https://journals.lww.com/ajg/fulltext/2023/10001/s1070_communication_gap_between_patients_and.1609.aspx

CONFIDE Survey Results

Bowel urgency is just as much of an issue in CD as it is in UC



Symptoms Most Impacting QoL in CD

Bowel
urgency

Pain

Fatigue

Far-reaching negative impact

Depression, anxiety, stress

Unpredictability leads to feelings of
loss of control

Missing out on relationships,
staying home, leading limited lives

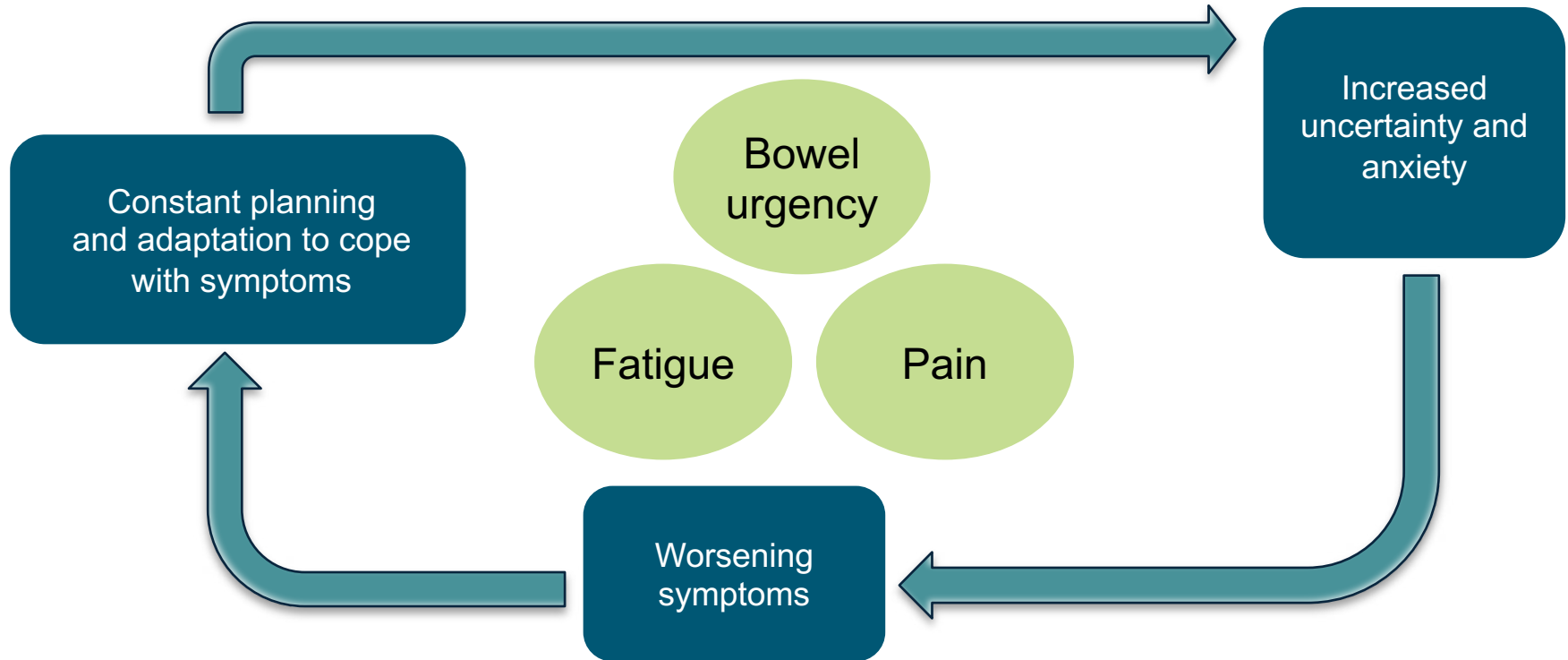
Fear of stigma due to symptoms:
unpredictable symptoms of fatigue,
odor, incontinence, pain, etc.
“What will people think?”

Missed time at school or work,
limited social engagement

QoL = quality of life

Adapted from Dibley L, et al. *Dig Dis Sci*. 2021;66(10):3330-3342. Dibley L, Norton C. *Inflamm Bowel Dis*. 2013;19(7):1450-1462.

Symptoms Most Impacting QoL in CD

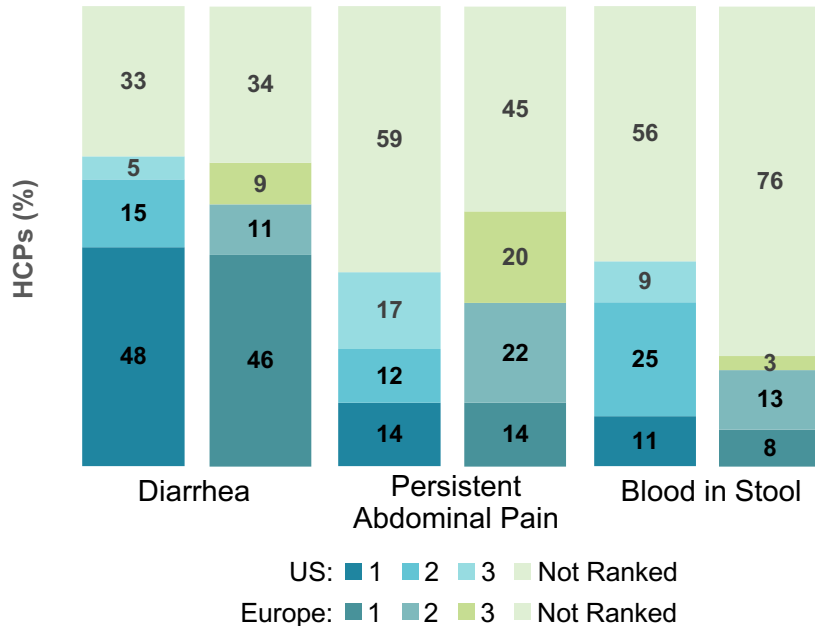


CONFIDE Survey Results

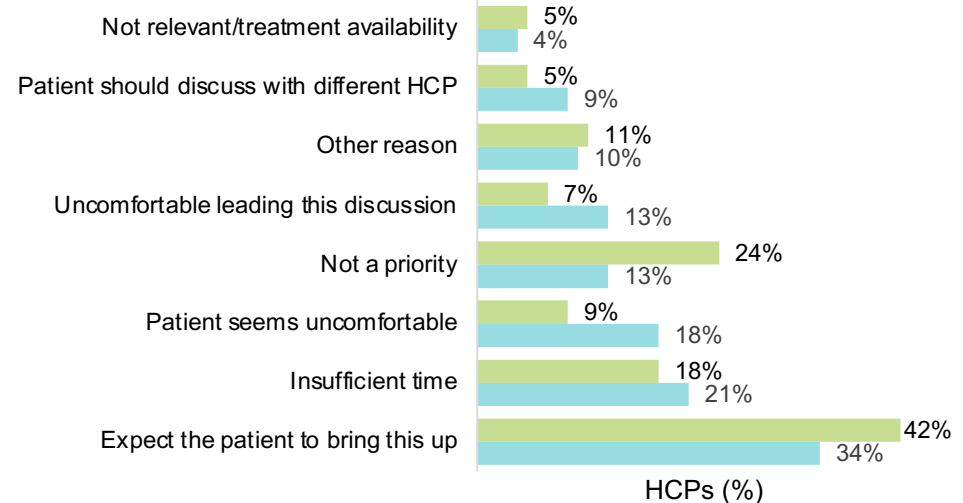
81% of US and 85% of European HCPs **did not rank bowel urgency** among the symptoms most reported by patients

HCPs **do not proactively discuss bowel urgency and bowel urgency–related accidents** with patients

Ranking of HCP-perceived top three CD symptoms reported by patients



HCP-reported reasons for not proactively discussing bowel urgency



HCPs = health care professionals

Schreiber S, Gibble TH, Dubinsky MC, et al. *Am J Gastroenterol.* 2023;118(10S):S815.
https://journals.lww.com/ajg/fulltext/2023/10001/s1070_communication_gap_between_patients_and.1609.aspx.

Urgency Can Occur Without Changes in Stool Frequency

Does normal stool frequency mean no bowel urgency?



55% of patients report urgency symptoms with no change in stool frequency



Patient Video



Commonly Used CD Disease Activity Indices

- Clinical Disease Activity Index (CDAI)
- Harvey-Bradshaw Index (HBI)
- Inflammatory Bowel Disease Questionnaire (IBDQ)
- Patient reported outcome-2 (PRO-2)

None of the commonly used scales capture bowel urgency severity

Simple Clinical Colitis Activity Index for UC

Bowel frequency (day): ____

- a. 0-3 (0)
- b. 4-6 (1)
- c. 7-9 (2)
- d. > 9 (3)

Bowel frequency (night): ____

- a. 0 (0)
- b. 1-3 (1)
- c. 4-6 (2)

General well-being (0-10): ____

- a. 7 or more (very well) (0)
- b. 6 (slightly below par) (1)
- c. 5 (poor) (2)
- d. 6 (very poor) (3)
- e. < 4 (terrible) (4)

Urgency of defecation: ____

- a. None (0)
- b. Hurry (1)
- c. Immediately – toilet nearby (2)
- d. Incontinence (3)

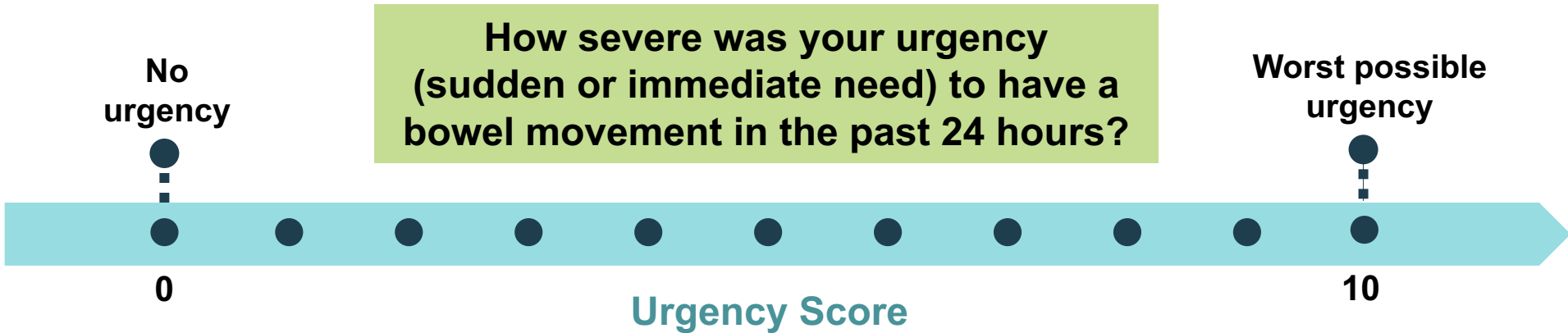
Blood in stool: ____

- a. None (0)
- b. Trace (1)
- c. Occasionally frank (< 50% of defecation) (2)
- d. Usually frank (> 50% of defecation) (3)

Extra colonic features (1 point for each that applies) – total: ____

- a. Arthritis (Y/N)
- b. Pyoderma gangrenosum (Y/N)
- c. Erythema nodosum (Y/N)
- d. Uveitis (Y/N)

Recent Innovations: Urgency Score for Adults with CD



- Bowel urgency is a distinct symptom of CD
- Urgency score is correlated highly with patient global rating of severity scores



Faculty Discussion

Role modeling
conversations about
bowel urgency



Patient Case: Margo L. 25 y/o woman



- **Reason for visit:** 3-month follow-up, medication review
- **History of present illness:** Diagnosed with CD 2 years ago, previous resection, CRP and fecal calprotectin normal 6 months ago, normal scope 8 months ago
- **Current treatment:** Infliximab 5 mg/kg every 8 weeks
- **Current symptoms:** BMs 3x per day, nocturnal BM 1-2x per week

Patient Statements

“I have a lot of days where I feel like my symptoms are taking everything out of me.”

“I feel tired from having to wake up at night.”

“I haven’t been able to make it to the bathroom in time twice this month and have started carrying extra clothes”

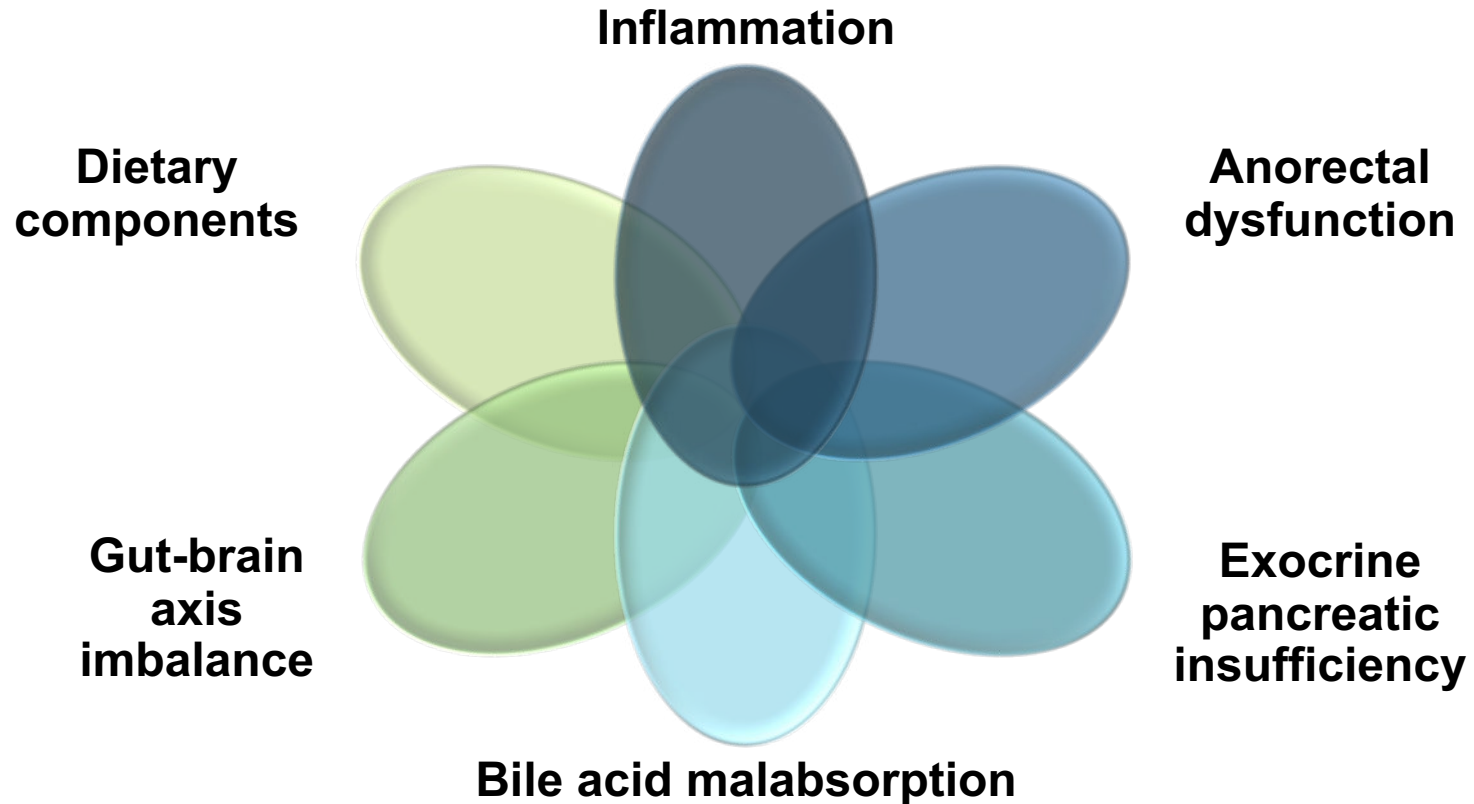


Faculty Discussion

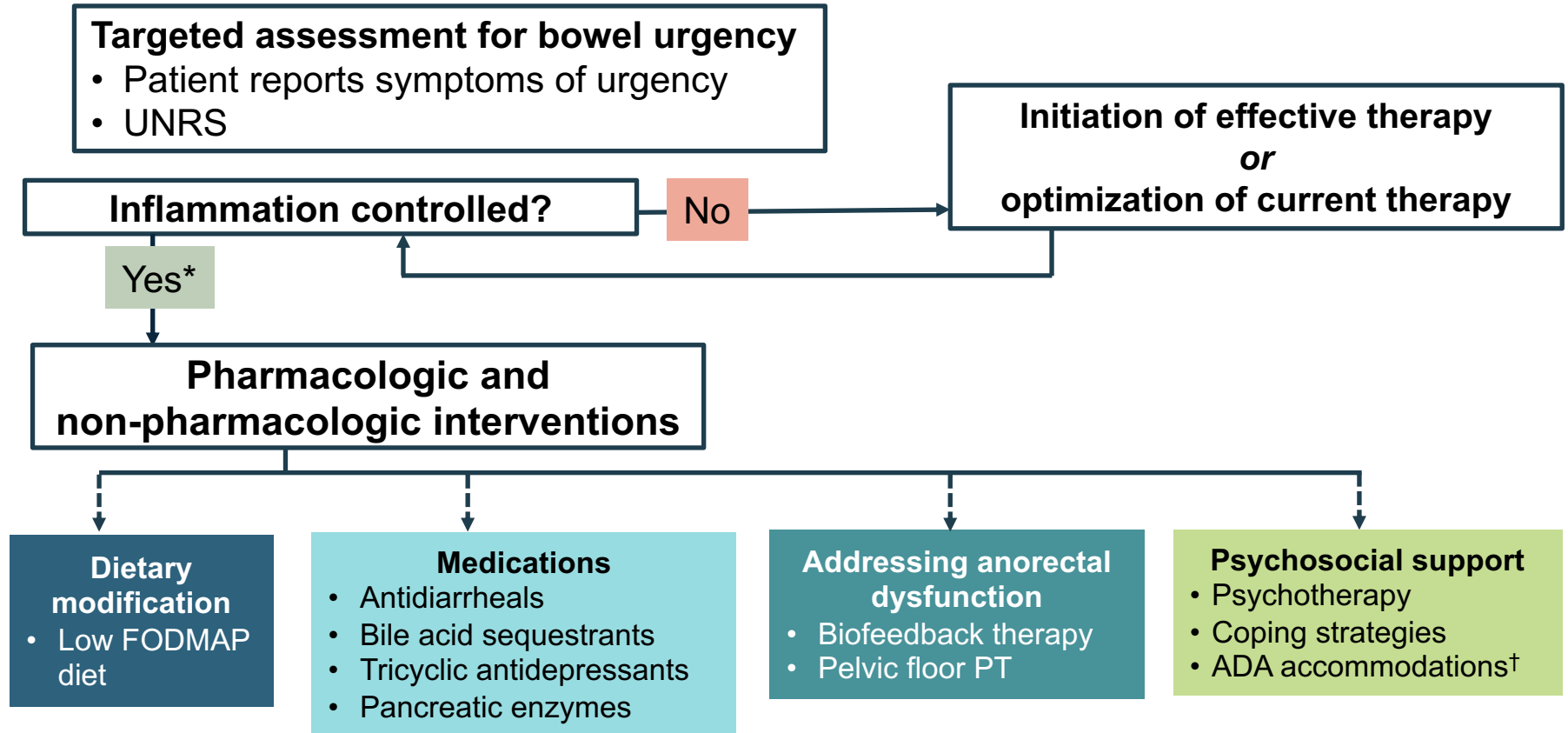
What is your approach
to this patient?



Factors That Can Influence Bowel Urgency in CD



Approach to Bowel Urgency



*Inflammation is controlled but urgency remains

†Americans with Disabilities Act (ADA) covers IBD due to bowel urgency

FODMAP = fermentable oligosaccharides, disaccharides, monosaccharides, and polyols; PT = physical therapy; UNRS = Urgency Numeric Rating Scale

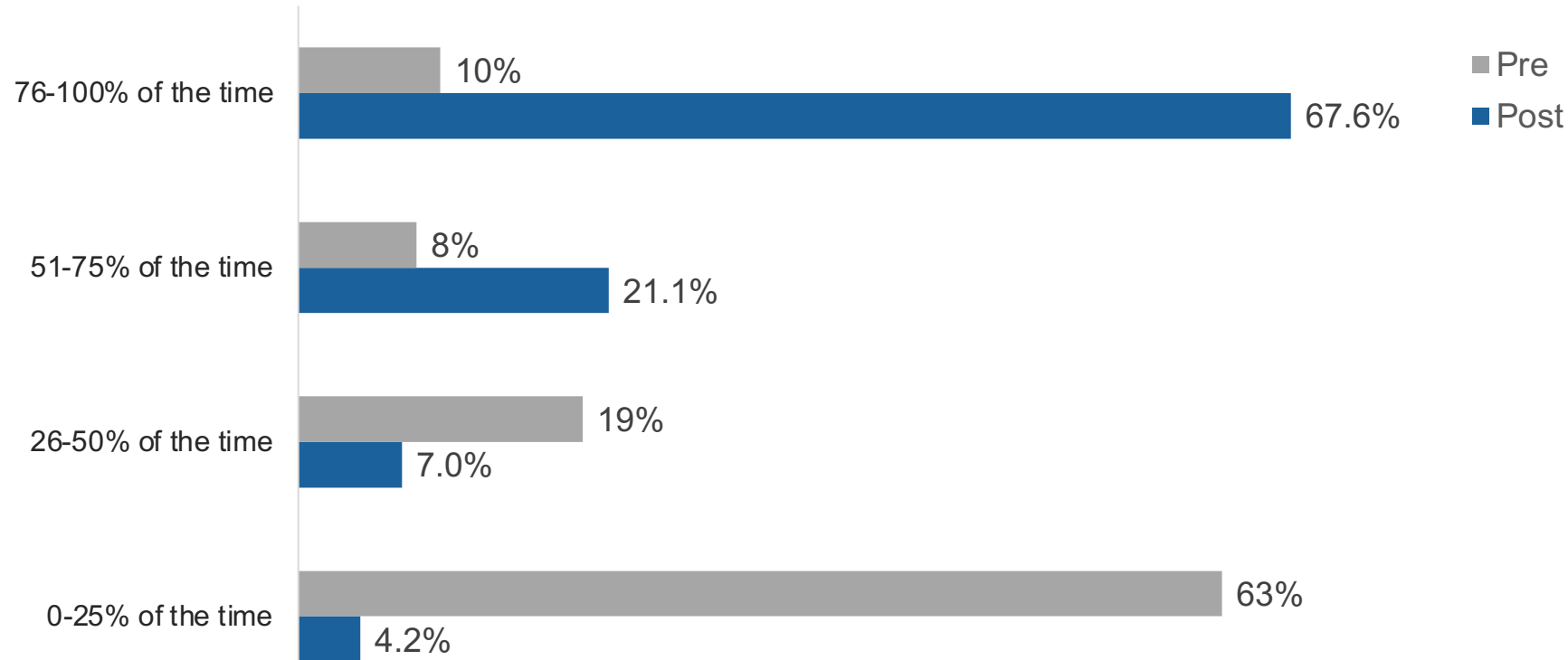
Adapted from Caron B, et al. *Clin Gastroenterol Hepatol.* 2023;21(6):1403-1413.e27. Americans With Disabilities Act (ADA) Website. www.ada.gov/law-and-regs/ada/.

Audience Response

Now how often will you incorporate bowel urgency assessments into your evaluation of patients with Crohn's disease (CD)?

- A. 0% of the time
- B. 1-25% of the time
- C. 26-50% of the time
- D. 51-75% of the time
- E. 76-100% of the time

Now how often will you incorporate bowel urgency assessments into your evaluation of patients with Crohn's disease (CD)?



Results recorded on April 3, 2024.

SMART Goals

Specific, Measurable, Attainable, Relevant, Timely

- Increase the percentage of patients with CD screened for bowel urgency.
- Improve the proportion of patients with CD who identify personalized treatment goals for addressing the impact of bowel urgency and other CD symptoms on daily life.

To Ask a Question

Please select the *Ask Question* tab below the slide viewer.

Please include the faculty member's name if the question is specifically for them.

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Questions & Answers



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