



Managing the Patient with IBD Throughout Life: Best Practices in Transitional Care

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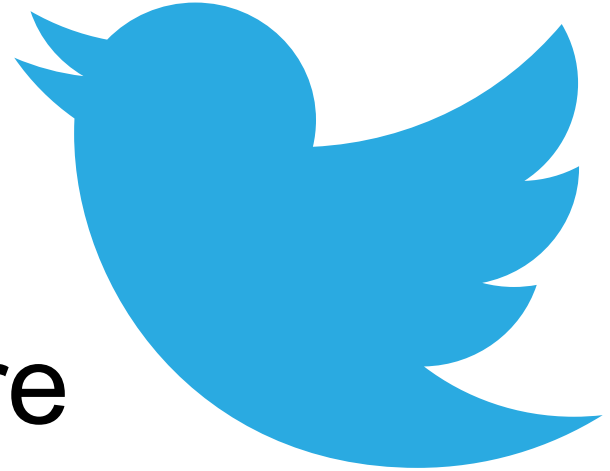
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**Learning
Objective 1**

Initiate multidisciplinary collaboration to provide optimal care for children and adolescents as they transition to adult care.



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Learning Objective **2**

Implement strategies to address disparities in care in patients with inflammatory bowel disease (IBD) by establishing trust, providing education, and engaging in shared decision-making (SDM).

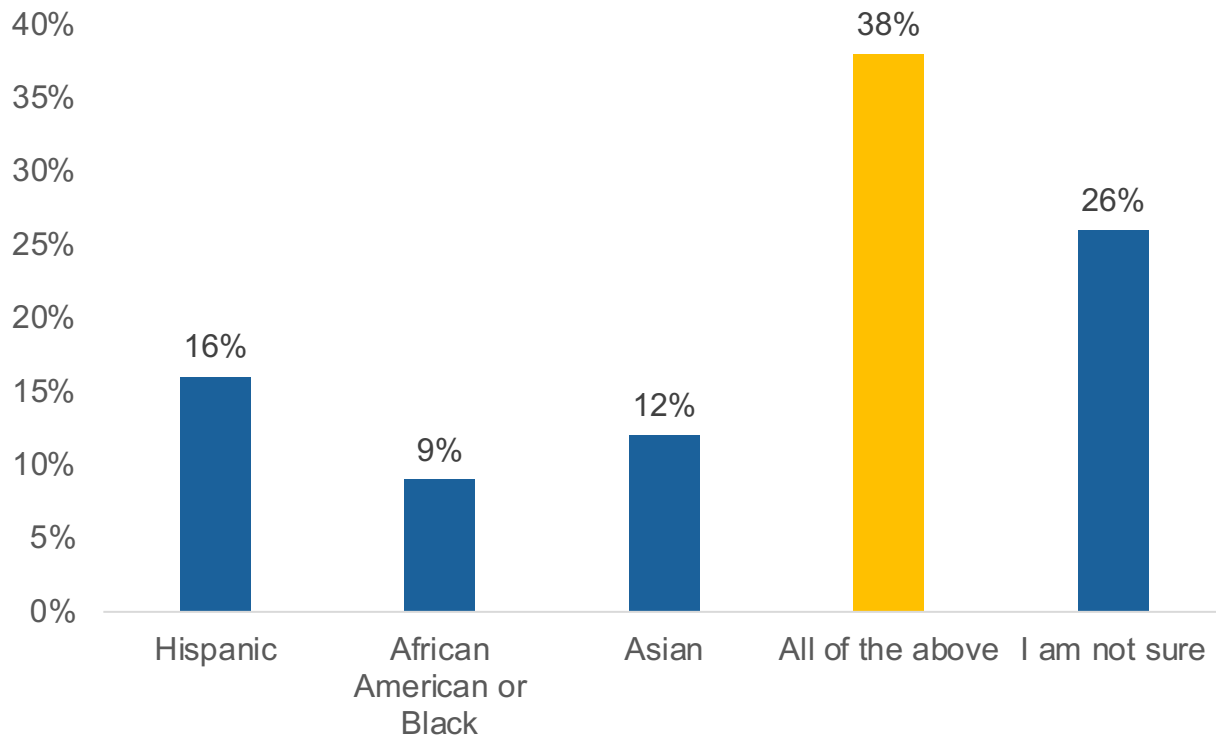


Audience Response

Population demographics of IBD in the United States are changing. Which population group is showing an increase in the incidence of IBD?

- A. Hispanic
- B. African American or Black
- C. Asian
- D. All of the above
- E. I am not sure

Population demographics of IBD in the United States are changing. Which population group is showing an increase in the incidence of IBD?



Changing Population Demographics of IBD

- Traditionally viewed as affecting individuals of Western and Northern European ancestry
- Incidence of IBD is increasing in non-White populations
- Population demographics are changing rapidly in the United States
- Important to increase understanding of race and ethnicity in disease outcomes

Case Study: Timothy

- 12-year-old African American male
- Referred by pediatrician for evaluation of abdominal pain and intermittent diarrhea x 2 months
- Noted plateau in growth chart x 2 years
- Mother reports that he has been a picky eater his whole life
- Patient seems reluctant to want to discuss gastrointestinal (GI) symptoms
- Labs: hemoglobin = 10.6, erythrocyte sedimentation rate (ESR) = 22

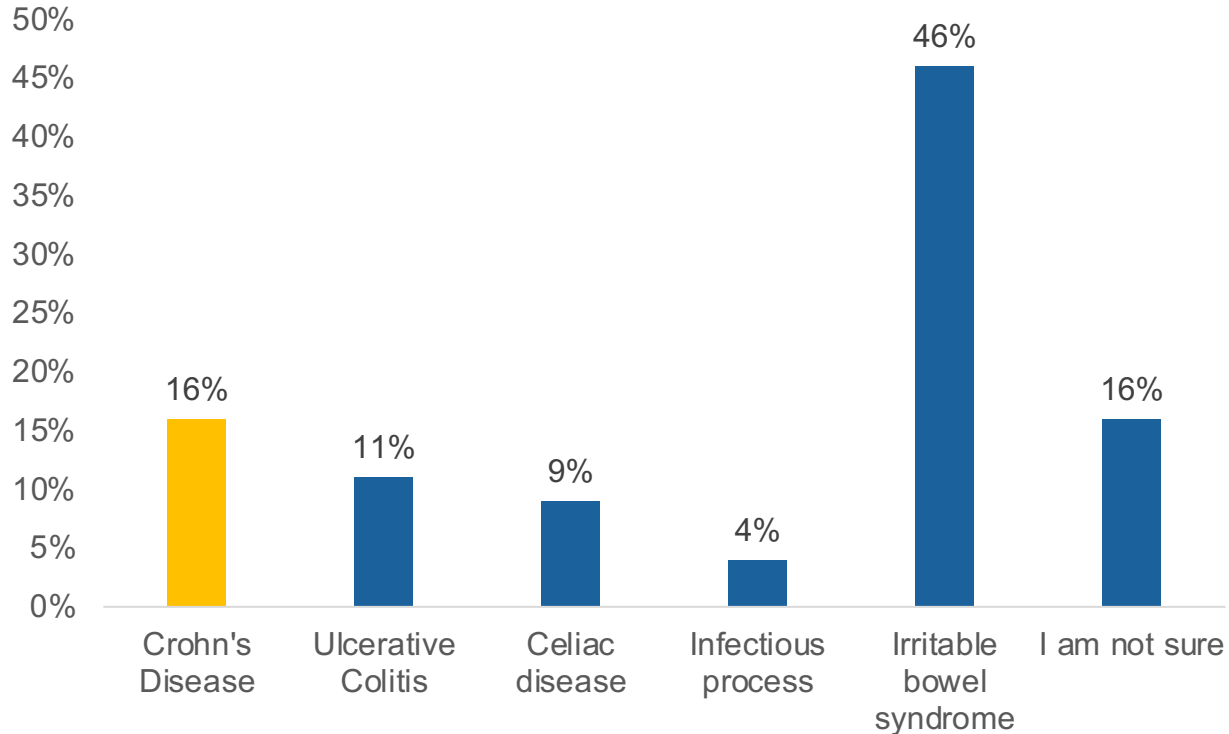


Audience Response

What would be your working diagnosis for Timothy?

- A. Crohn's disease
- B. Ulcerative colitis
- C. Celiac disease
- D. Infectious process
- E. Irritable bowel syndrome
- F. I am not sure

What would be your working diagnosis for Timothy?



Case Study: Timothy



- EGD with scattered ulcerations in the duodenum; colonoscopy with erythematous, ulcerated, and friable mucosa in the terminal ileum and cecum
- Perianal exam notable for skin tag and small fistulous opening
- MRE: noted bowel wall thickening in the distal ileum and ascending colon; patchy areas of thickened jejunum and a single perianal fistula (no abscess)
- Diagnosed with ileocolonic + upper tract Crohn's disease with perianal disease
- Started on 5 mg/kg IFX, 12.5 mg MTX weekly, and folic acid
- At 1-month follow-up reports improvement in abdominal pain

EGD = esophagogastroduodenoscopy; IFX = infliximab; MRE = magnetic resonance enterography; MTX = methotrexate

Pediatric IBD: General

- Wide range of symptoms
 - Weight loss, abdominal pain, diarrhea, rectal bleeding, puberty or growth delays
- Diagnostic evaluation
 - History and physical exam, labs, stool studies
 - Advanced diagnostics if findings suggest IBD
 - Imaging, endoscopy, colonoscopy
- Treatment goal
 - Induce and maintain durable disease remission
- Treatment strategy
 - Relieve symptoms, optimize growth, improve quality of life

Family-Centered Care

- What is it?

- A partnership approach to health care decision-making between the family and health care team

- Who is on the team?

- Gastroenterologist
- Surgeon
- Nurse coordinator
- Nurse practitioner
- Social worker
- Dietician
- Psychologist
- Clinical pharmacist
- Biologic navigator
- Data/QI coordinator
- Prior authorization team

IBD in Under-Represented Patients

- Increasing incidence of IBD
- Less likely to have family history of IBD
- Hispanic and Asian patients diagnosed with ulcerative colitis more often
- Increased utilization of emergency department

Quality Measures in Pediatric IBD

- Quality measures should address both the best care and the best outcomes
- Key measures to assess
 - Is the patient receiving the correct dose of medication?
 - Is blood testing being performed to monitor the patient appropriately?
 - Is the patient being evaluated often enough?
 - Are the extent and phenotype of the disease being assessed?
 - Is nutritional status being assessed?
 - Does the patient have active or inactive disease?
 - Does the patient have corticosteroid-free remission?

What Is Important to the Pediatric Patient with IBD?

- Remain as “normal” as possible
- School/psychosocial functioning
- Special accommodations for school
- Transition to college

Case Study: Timothy

- 12-year-old African American male
- Has not received flu shot
- Received annual eye exam
- Annual skin exam to be done next month
- He has now had IBD for approximately 1 year

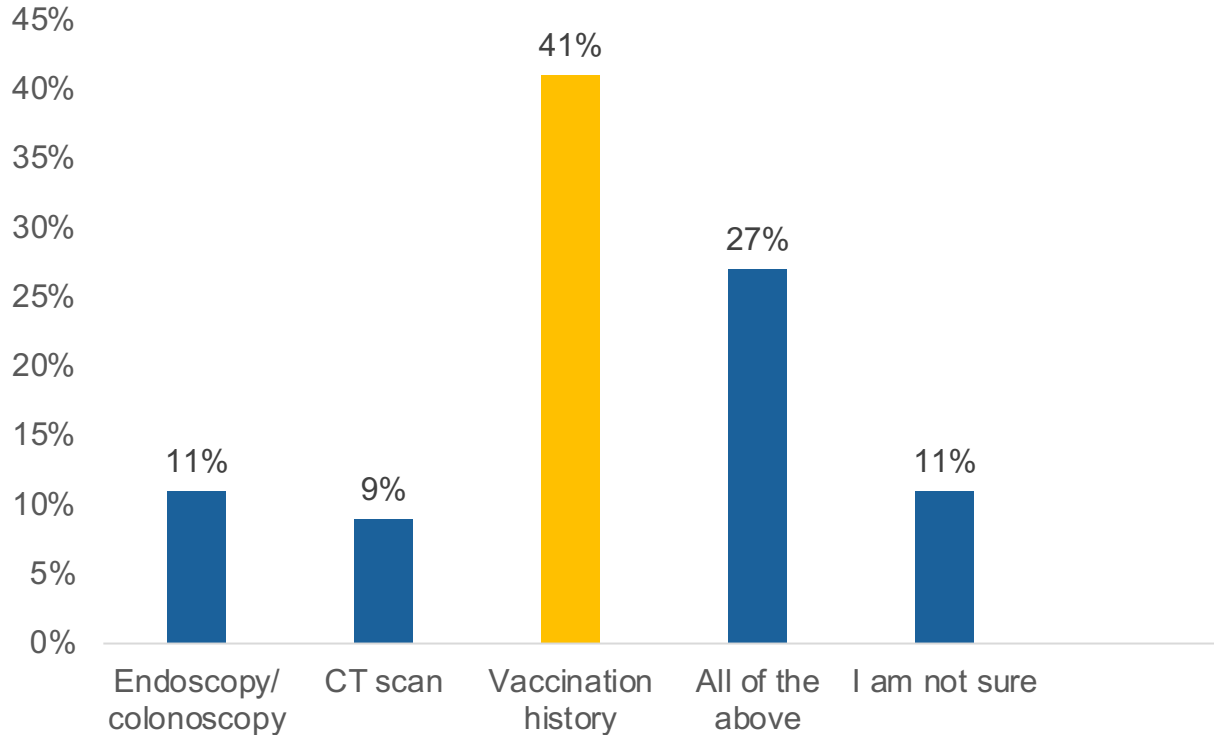


Audience Response

Which important information is missing from Timothy's chart?

- A. Endoscopy/colonoscopy
- B. Computed tomography (CT) scan
- C. Vaccination history
- D. All of the above
- E. I am not sure

Which important information is missing from Timothy's chart?



Health Care Transition

- Purposeful, planned movement of adolescents and young adults from *child-centered* care to *adult-centered* care
- **Transfer** of care to adult provider
- **Transition** of responsibility and decision-making from care providers (such as parents) to patient

Potential Differences Between Pediatric and Adult Medical Services

Pediatric	Adult
Multidisciplinary	Single provider
Family focused	Patient focused
Less availability of clinical trials	More availability of clinical trials
Fewer FDA-approved treatments	More FDA-approved treatments
Parental direction and consent required	Patient expected to be autonomous and directed

Transferring to Adult Gastroenterology Care

When?

Age 18-22

Who?

Patients who are ready to take on the primary role in managing health care

Why?

Patients are adults now, not “big children”

Benefits

- Adult providers focused on and have resources for treating adults
- Access to additional treatments and clinical trials
- Successful transition important in maintaining continuity of care

Concerns of Transitioning Patients

- Patients and families report the concern that they are moving to less excellent care
- Patients may report sense of abandonment
- Before transfer, few identify any benefit to transfer
 - Some find increased independence a benefit after transfer
- Many find the variability in time of transfer unfair

Case Study: Timothy

Transitioned to Adult Care

- 20-year-old African American male
- Transferred from pediatric GI 4 months ago
- Presents with flaring
- Reports challenges getting infusions on time and stopped taking MTX since being on his own
- Bloodwork shows antibodies to IFX
- Discussed best treatment option
 - Recommend switching from IFX to another biologic



What Is SDM in IBD?

- In SDM the patient and health care professional work together to decide the best plan of care
- SDM in pediatrics involves the child or adolescent patient, the caregiver(s), and the clinician
- The patient's values, goals, and concerns are considered
- SDM helps patients learn more about their health condition, treatment options, and risks/benefits

Resources

- Crohn's & Colitis Foundation (CCF)

<https://www.crohnscolitisfoundation.org/science-and-professionals/education-resources/clinician-resources>

- NASPGHAN

https://www.naspghan.org/files/documents/pdfs/medical-resources/ibd/Checklist_PatientandHealthcareProdiver_TransitionfromPedtoAdult.pdf

- ImproveCareNow

<https://www.improvecarenow.org/tools>

<https://www.improvecarenow.org/program-details>

Issues to Address During Transition to Adult Care with All Patients

- Medications and adherence
- Mental health
- Health literacy
- Legal issues with parents
- Financial issues
 - Insurance, employment status
- Limited clinical trial data for under-represented patients
- Social determinants of health

SMART Goals

Specific, Measurable, Attainable, Relevant, Timely

- Recognize the increasing incidence of IBD in under-represented patients
- Ensure pediatric patients with IBD have family-centered, team-based care
- Prepare patients for transition longitudinally and address all concerns of the patient and family
- Integrate checklists and regular assessments in your care of all patients with IBD to evaluate the whole patient and especially during transition of care

To Ask a Question

Please click on the *Ask Question* tab and type your question. Please include the faculty member's name if the question is specifically for them.



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