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2023 ACG HEPATOLOGY SCHOOL & EASTERN REGIONAL POSTGRADUATE COURSE
JUNE 2–4, 2023 | RENAISSANCE HOTEL WASHINGTON, DC

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Participating in the Webinar

All attendees will be muted and will remain in “Listen Only Mode.”

Type your questions here so that the moderator can see them. Not all questions will be answered but we will get to as many as possible.

A handout with the slides and room to take notes can be downloaded from your control panel.
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Week 21 – Thursday, May 25, 2023
The Role of Non-Invasive Modalities in Colorectal Cancer Screening
Faculty: Douglas J. Robertson, MD, MPH
Moderator: T.R. Levin, MD, FACC
At Noon and 8 pm Eastern

Week 22 – Thursday, June 1, 2023
Prior Authorization in GI: Tips from the ACG Prior Authorization Task Force
Faculty: Baharak Moshiree, MD, MSc, FACC, and Stephen T. Amann, MD, FACC
Moderators: Daniel J. Pambianco, MD, FACC, and Dayna S. Early, MD, FACC
At Noon and 8 pm Eastern

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OCTOBER 20–25, 2023
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Disclosures

Sandra C. Kim, MD
Dr. Kim has no financial relationships with ineligible companies.

Amy Bugwadia, MS
Ms. Bugwadia has no financial relationships with ineligible companies.

Mara Shapiro, BA
Sandoz Pharmaceuticals: Speaker (terminated)

*All of the relevant financial relationships listed for these individuals have been mitigated
Crash Course in Caring for the Emerging Adult Living with IBD: It’s NOT “Mission Impossible”

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Cleveland Clinic
Children’s Hospital

Amy Bugwadia, MS
Stanford University
School of Medicine

OBJECTIVES

- Define the concepts of transitioning and transfer of care for young adults with IBD
- Recognize the psychological impact of IBD for the transitioning adolescent and their caregivers
- Discuss common barriers to care
- Review factors that prepare the adolescent patient to successfully transfer and transition to adult care
- Develop a transition plan/expectations that includes the pediatric and adult GI providers, young adult patient, and family
- Provide resources and tools to help in these processes
The Road to Independence

- Crucial to start/ramp up transitioning process early
  - Gradual process: parents shift into role of “coach”
  - Preparation for being away from home after high school
- Adult GI teams will expect young adults to be independent

What is Transitioning?

- Transition ≠ Transfer
- Transfer of care
  - Moving from one provider to another
- Transition
  - Planned, purposeful process of adolescent patients towards independence from pediatric to adult–focused healthcare systems
  - Flexible, dynamic process
  - *Timing important
NASPGHAN: Transitioning of Care

“The goal of a transition program is to achieve for each chronically ill patient a continuum of care that includes normalization of social and emotional development and the acquisition of independent living skills.”

- NASPGHAN Medical Position Statement 2002

- Overall per-patient costs greater in children vs. adults
- Lifetime cumulative costs highest in patients with earlier onset IBD

Greatest Gaps Noted in Psychosocial Care

<table>
<thead>
<tr>
<th>Annual check-up</th>
<th>Routine vaccinations</th>
<th>Care for minor illnesses</th>
<th>Check-up for GI symptoms</th>
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<tbody>
<tr>
<td>70</td>
<td>78</td>
<td>24</td>
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</tr>
<tr>
<td>(9)</td>
<td>(10)</td>
<td>(7)</td>
<td>(10)</td>
</tr>
</tbody>
</table>

| Monitor IBD activity | Change IBD treatment | Discuss family relationships | Discuss peer relationships | Discuss school grades | Discuss extracurriculars | Discuss mood | Discuss puberty |
|----------------------|----------------------|-----------------------------|---------------------------|-----------------------|--------------------------|-------------|----------------|}
| %                    | %                    | %                           | %                         | %                     | %                        | %           | %              |
| PCP                  | GI                   | PCT&GI                      | Other                     | No receipt            |                          |             |                |


Psychosocial Development is Delayed in Adolescent IBD Patients

<table>
<thead>
<tr>
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<th>Patients with IBD</th>
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<td>Leaving the parents' home</td>
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<tr>
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<tr>
<td>Low</td>
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<tr>
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<td>Marital status</td>
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<tr>
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<tr>
<td>Single</td>
<td>96.9</td>
<td>31</td>
</tr>
</tbody>
</table>

IBD = inflammatory bowel disease.

*P < 0.001 according to logistic regression analysis by group, age, and sex.

Hummel, et al. 2013. JPGN
School Functioning and Performance Affects K-12, Higher Ed, and Beyond

- Children with IBD have poorer school functioning compared to healthy children
  
  
  - Poorer functioning but only significant differences were in absences (although decreased GPA and QOL as well)

- Predictors for worse educational outcomes:
  
  (Singh, et al. 2015. J Peds)
  
  - Age, gender–matched children with IBD to controls
  
  - Predictors: *Lower SES and diagnosis with mental health issues, but not age at diagnosis, IBD type, steroids, or hospitalizations

- Higher ed can impact future jobs, economic/insurance status
  
  
  - More difficult adjustment to college, lower attendance and self-efficacy for students with IBD (especially when experiencing symptoms)

Adolescence to Adulthood…
Is It REALLY a Seamless Process?
### Considerations for Care in Young Adults

- Shift in roles
- Social pressures
- Developmental changes
- Life changes
- Issues of confidentiality
- Redefining responsibility
- Financial and insurance considerations
- Increasing independence and autonomy
- Shared-decision making

### Transitioning in IBD Care

- Adolescent IBD patients have low baseline knowledge of disease
- Discrepancies in adult vs. pediatric GI MD perceptions of patient readiness
  - Inadequate disease knowledge, lack of self-advocacy
  - Insufficient time/clinical resources
- Poor correlation between clinician vs. measures - defined health literacy readiness in adolescent IBD patients
  - Lowest correlation in patient-reported self-efficacy in disease management
  - Differences in how clinicians and patients define health literacy

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Boamah, et al. 2010. JPGN
Benchimol, et al. 2011, Inflamm Bowel Dis
Huang, et al. 2012, Clin Gastro Hepato
Psychosocial Readiness in Young Adults

- Adult GI MD: Self – efficacy most important
- *Psychosocial readiness more important than age
- Barriers: poor medical handoff; patient lack of self-responsibility

Effective Transitioning Impacts Clinical Outcomes

- TRANSIT study: GI centers in the UK
- “Structured transition.” > 2 GI visits (Peds + Adult GI clinicians)
- *Disease flares significantly less in transition group
- *Higher steroid – free remission in transition group (71% vs 41%)
Transitioning from Pediatrics to Adults…

- Recognizing and reconciling differences in approaches to care
  - Differences in style
  - Differences in management
  - Differences in time allotted for office visit
  - Differences in procedures and sedation
- Planning for care at college/time away from home
- Balancing parent and patient interests

Health Maintenance is NOT Just About Medication

- Maintaining a healthy diet
- Taking meds, filling prescriptions, remembering to make appointments
- Knowledge about type of illness and meds
- Seeking medical attention appropriately, attending follow-up appointments
- Physical activity
- Other behaviors – sexual, smoking, contraception
- Immunizations

Adherence
How Can Adult GIs Effectively Address This?

- Many Pediatric GIs currently use:
  - Readiness assessments
  - Utilization of checklists
  - Educational and self-management tools
  - Written comprehensive healthcare plan

- Adult GIs can consider implementing…
  - Dedicated clinics for the adolescent (annual visits)
  - Dedicated APP/Nurse Coordinator
  - Discussions of the Transition Readiness domains during initial visits

Transition Readiness Tools

Patients
- Medication management
- Appointment keeping
- Tracking health issues
- Managing ADL
- Communication with providers

Patients, parents, caregivers
- Transition importance and confidence;
- My health
- Skills for using health care
So... What Are We Missing in the Transition Process?

Medical Summary

- Date of (and age at) IBD diagnosis
- IBD phenotype: Disease distribution/severity
- IBD-related surgeries and complications
- Medication/therapy history (including prior adverse reactions)
- Diagnostic testing results: most recent endoscopies and imaging
- Vaccination/screening status: Hepatitis B, pneumococcal vaccines; TB status
- Recent labs (including TDM results)
What to Discuss with Young Adult Patients

“Administrative” issues related medical care

- Accommodations
  - College (Disability office; letters/forms)
  - Academic internships/work programs
  - Work – related (FMLA)
- Dealing with insurance mandates
  - Type of insurance and coverage
  - Understanding insurance versus pharmacy benefits manager (PBM)
  - Prior authorizations
* Not everyone needs to be a health policy expert! But patients do need a baseline understanding in order to be an active partner in their care!

What to Discuss with Young Adult Patients

- Health management
  - Emergency support/contacts (and disclosure)
  - Knowing where to get your medications, and how to use them
  - Scheduling visits, tests, and procedures
  - Knowing when and how you should contact your healthcare team
- Health maintenance
  - Understanding medication interactions
  - Understanding self-protection in the time of COVID (and other future pandemics/viral seasons)
  - Sexual health and family planning
Resources to Provide Your Patients

The Transfer Toolkit
A guide for young people with IBD, their families, and their care teams with tools and stories to ease the transition to adult care

Crohn’s and Colitis Young Adults Network

WHO WE ARE
The CCYAN is a community and international fellowship program for young adults with IBD.

OUR FELLOWSHIP
We facilitate a yearlong fellowship that brings together a select group of young adults with IBD from around the world. Our fellows produce monthly content, convene virtually to hear from influential speakers, engage in speaking opportunities and receive a stipend for their participation.

AND MORE...
• Virtual community meetings for young adults with IBD
• Roundtable on Young Adults with IBD
  a yearlong learning community comprised of monthly discussions between patients and providers
• IBD Medical Student Scholars
  a unique program for medical students interested in gastroenterology and internal medicine to learn about the global challenges and needs of adolescents and young adults with IBD
**Peer Support Networks**

- Crohn’s and Colitis Young Adults Network (CCYAN)
  - [Resources](#) and virtual meetings
- ImproveCareNow Pediatric Advisory Council (PAC)
- Crohn’s and Colitis Foundation
  - National Council of College Leaders (NCCL) and [Campus Connection](#)
  - Young Professionals Groups (Chapter-specific)
  - Camp Oasis (Counselors)
  - [Power of Two](#) program
- Clinic and hospital-based support groups
- College-based groups
  - Student clubs, Disability Office events
- Fostering 1:1 mentorship/connections

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**Psychosocial Readiness → Routine Practice**

- **Pediatric GI MD:**
  - Be proactive and provide appropriate resources for young adult patients
  - Focus on patient self – management of their disease…and life
  - Ask the tough questions!
  - Have a comprehensive medical summary ready
- **Adult GI MD:**
  - Collaborate with the peds team in the early stages of care transfer
  - Anticipate existing gaps of knowledge and self – management skills
  - Prepare for more time for questions, additional education… and parents
Teamwork is the Key to Success

- Transition of medical care coincides with other life transitions, which may or may not promote effective medical transition
  - School and college
- Transition is a gradual process (“continuum of care”) of achieving autonomy as an independent young adult in medical care and overall health management
- One size does NOT fit all!
- Transition is most successful when patients, parents, AND clinicians are involved.

Ultimate Goals

- Empower your emerging adult patients
  - Acknowledge the challenges they are encountering as they form their own identity as a young adult with a chronic illness
- Ensure that there is an effective therapeutic alliance
  - Shared decision making on all levels
  - Open communication
  - Safe space
- Educate on available resources
  - Within the healthcare institution
  - Additional scientific and patient-focused information
Questions

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