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Trio of Papers on Pediatric IBD Focuses on Gaps in Care, Patterns and Locations of Care, and Patient Perspectives

July and September saw a trio of new papers¹⁻³ on inflammatory bowel disease (IBD) in pediatric patients from researchers in the Division of Pediatric Gastroenterology, Hepatology, and Nutrition at UPMC Children's Hospital of Pittsburgh.



Former UPMC Children's fellow Hilary K. Michel, MD, and nationally recognized IBD expert **Sandra C. Kim, MD**, director of the Inflammatory Bowel Disease Center at UPMC

Children's teamed up on the studies with Robert B. Noll, PhD, professor of pediatrics, psychiatry, and psychology at the University of Pittsburgh School of Medicine, and Nalyn Siripong, PhD, from the University of Pittsburgh Clinical and Translational Science Institute.

Broadly, the three papers deal with gaps in the comprehensive care of pediatric IBD patients and their caregivers; patterns of care for IBD patients across the spectrum of care settings (e.g., primary care, ED visits); and direct patient and caregiver perspectives and perceptions on what constitutes quality care and what is the ideal model of comprehensive care for IBD patients. The latter study is the first of its kind to examine and catalog direct patient and caregiver perspectives on the subject.

Data for each study was derived from cross-sectional surveys that included two cohorts: parents of children aged 2-17 with

IBD and adolescents with IBD between the ages of 13-17.

Searching for Gaps in Care

The first study, published in the *Journal of Pediatrics* in September, examined patient and parent perspectives on patterns of care delivered by primary care and specialty (GI) providers and what, if any, gaps exist in care.

While the vast majority of respondents to the surveys indicated that basics of care such as annual wellness visits and vaccinations were attended to by their regular primary care physicians (PCP), and GI specific follow-up care for IBD symptom management, IBD monitoring, or potential adjustments to IBD medication therapies were handled by their attending gastroenterologist, significant portions of each study cohort identified areas of care that were not addressed routinely by any of their providers.

Discussions about the patient's mood, interpersonal relationships with family members and friends, and activities or possible school difficulties appear to be lacking. Between 30% and 40% of study participants indicated that these discussions were absent from their health care providers' interactions.

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For older adolescents, discussions and care around issues related to substance use or abuse, sexual health, or how their body image has been affected by their diagnosis and treatment are lacking.

A full three-quarters of adolescents and parents of adolescents indicated a total lack of discussion or planning with their health care providers about how their care would eventually transition to an adult gastroenterology provider as they grew older.

“While our study has limitations, there does appear to be a lack of coordinated care and discussions related to patient health outside of their IBD condition. While their basic physical health and IBD-specific care needs are being met by their PCP and GI providers, there is a real perception that vital discussions that could uncover more serious psychosocial effects or behavioral health conditions are missing. Knowing how important transitions of care are to ensure continuity of health, the fact that 75% of survey respondents indicated that their providers did not conduct discussions around transitions in care means there is much more we can do to construct a timelier and more uniform process for transitioning care,” says Dr. Kim.

Patterns of Care and the Importance of Patient and Caregiver Perspectives in Developing Comprehensive Care Models

Two additional studies from Michel et al. on related IBD topics were published in July and September. The first, in the *Journal of Pediatric Gastroenterology and Nutrition*,² examined patterns of care and utilization across various health care settings by pediatric IBD patients. The second study, published in *Crohn's & Colitis 360*, examined patient and caregiver perspectives on what constitutes ideal and quality care for pediatric IBD patients, and what barriers exist to receiving this kind of comprehensive care.

Findings from the paper on care patterns included a greater-than-expected use of the emergency department (ED) and urgent care

(UC) locations by survey respondents. Some of the factors or differentiators between respondents that contributed to higher ED or urgent care utilization include caregiver's education level, geographic distance from GI specialist, and those who had more frequent PCP visits. Higher levels of ED or UC usage, the authors surmise, may ultimately contribute to worse outcomes because the fragmentary nature of this care can lead to disjointed communications between providers in various settings and disparate health care systems.

In the *Crohn's & Colitis 360* paper, Michel et al. provide their findings from a first-of-its-kind study examining patient and caregiver preferences for the type of care they receive as IBD patients. The study sought to collect direct perspectives from patients and caregivers on what they consider to be ideal care for their condition, who should provide which aspects of that care (e.g., between primary care providers and GI specialists), and what barriers may exist that can prevent receiving ideal, high-quality care for their IBD.

“I think there several important takeaways from these studies. We need to engage with our patients and their caregivers much more directly to help shape the nature of our care models. That may sound intuitive, but it has been somewhat overlooked to this point.

We also should understand that our patients likely have many more concerns on their minds beyond their IBD condition proper.

Psychosocial and behavioral health issues can have a tremendous impact on one's overall health and quality of life. As GI providers, the key is keeping this top of mind and becoming more proactive in screening for and addressing these potential concerns with patients,” says Dr. Kim.

References

- ¹ Michel HK, Kim SC, Siripong N, Noll RB. Gaps Exist in the Comprehensive Care of Children With Inflammatory Bowel Disease. *J Pediatr*. 2020 Sep; 224: 94-101.
- ² Michel HK, Noll RB, Siripong N, Kim SC. Patterns of Primary, Specialty, Urgent Care, and Emergency Department Care in Children With Inflammatory Bowel Diseases. *J Pediatr Gastroenterol Nutr*. 2020 Jul; 71(1): e28-e34. Epub ahead of print.
- ³ Michel HK, Siripong N, Noll RB, Kim SC. Caregiver and Adolescent Patient Perspectives on Comprehensive Care for Inflammatory Bowel Diseases: Building a Family-Centered Care Delivery Model. *Crohn's & Colitis 360*. 2020; 2(3): Ottaa055. Epub ahead of print.

More About Dr. Kim

Sandra C. Kim, MD, a nationally recognized expert in pediatric and adolescent inflammatory bowel diseases, is the Director of the Inflammatory Bowel Disease (IBD) Center, a part of the Division of Pediatric Gastroenterology, Hepatology, and Nutrition at UPMC Children's Hospital of Pittsburgh. Dr. Kim is also associate professor of Pediatrics at the University of Pittsburgh School of Medicine. Dr. Kim's clinical and research interests focus on pediatric inflammatory bowel diseases, including adolescent transitioning and quality improvement in pediatric IBD and the impact of the gastrointestinal microbiota in IBD. Her research has been funded by the National Institutes of Health and the Crohn's and Colitis Foundation. She has authored numerous studies on pediatric and adolescent inflammatory bowel diseases. Dr. Kim served as past chair of Pediatric Affairs and serves as the current chair of Government Affairs/Advocacy for the Crohn's and Colitis Foundation (CCF) nationally. In addition, she serves on the Physician Leadership committee for Improve Care Now, a national pediatric IBD quality improvement collaborative. As a reflection of her dedication to her profession, Dr. Kim was awarded the 2011 and 2018 Rosenthal Awards for her leadership in patient education and advocacy by the CCF. In addition, she was one of the Foundation's 2020 Uniting to Care and Cure recipients.

Division News

Updates from NASPGHAN 2020

Even though the COVID-19 pandemic foiled plans for an in-person meeting, the 2020 North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) annual meeting was still conducted through a virtual platform, allowing clinicians and researchers from across north American and beyond the opportunity to learn and present new findings from their areas of specialty. NASPGHAN 2020 was held November 1-7, 2020.

UPMC Children's Hospital of Pittsburgh Division of Pediatric Gastroenterology, Hepatology, and Nutrition faculty were well represented at the virtual event. Below is a summary of highlights from faculty who presented and contributed to scientific program.



Arvind Srinath, MD, (above, far left) associate professor of Pediatrics and director of the pediatric gastroenterology fellowship program at UPMC Children's served as a co-director of the Teaching & Tomorrow residency recruitment and informational program for the 2020 NASPGHAN/APGNN annual meeting. Dr. Srinath also gave a lecture during the program during the first day's programming on "How to Navigate Virtual NASPGHAN."

Division Fellow, **Vikram Raghu, MD**, (above second from left) received a 2020 NASPGHAN Foundation Innovations in Clinical Care Grant.

Whitney Gray, CRNP, (above, third from left) was elected to the APGNN leadership as Media Chair.

Division Fellow, **Mary Ayers, MD**, (above, far right) gave a poster presentation on "Understanding the Role of Beta-Catenin and FXR in Cholestatic Liver Disease with Therapeutic Opportunities in Murine Model." Dr. Ayers also was selected to join the NASPGHAN Hepatology Committee.

Congratulations to former Division Chief **Mark Lowe, MD**, who was the 2020 Shwachman Awardee for his lifetime accomplishments in pediatric gastroenterology.

News, Awards, and Accolades

Sandra C. Kim, MD, was nominated for the Distinctive Physician Award by UPMC Children's Hospital of Pittsburgh.

Anne Greci, CRNP, and **Kimberly Ackerman, CRNP**, were nominated for the Distinctive APP Award by UPMC Children's Hospital of Pittsburgh.

James Squires, MD, MS, was appointed as an Associate Editor of the *Journal of Pediatric Gastroenterology and Nutrition*. Dr. Squires also was awarded the Eugene Washington PCORI Engagement Award to establish comparative effectiveness and patient-centered outcomes research in pediatric liver transplant recipients.

Vikram Raghu, MD, was awarded the UPMC Children's K12 scholarship to investigate cost-effectiveness and optimization of pediatric intestinal transplant.

2020 AIBD Virtual Program

The 2020 Advances in Inflammatory Bowel Diseases annual meeting was held virtually on December 9-12, 2020.

Sandra C. Kim, MD, director of the IBD Center at UPMC Children's, was a co-chair of the pediatric sessions and a member of the steering committee for the conference. Additionally, Dr. Kim participated in numerous sessions during the conference. These included:

- Special Considerations in the Management of Young(er) Patients
- Q&A Panel Discussion: Illuminating the Circle of Life in IBD
- Q&A Panel Discussion: Advances in Pediatric IBD
- Multidisciplinary Case Discussion I: Acute Severe Indeterminate Colitis
- Multidisciplinary Case Discussion II: Multidisciplinary Management of Intra-Abdominal Abscess
- Multidisciplinary Case Discussion III: Complicated Pouch

11th Annual Pediatric Intestinal Failure and Rehabilitation Symposium

2020 saw the 11th Annual Pediatric Intestinal Failure and Rehabilitation Symposium, an event founded in Pittsburgh by UPMC Children's Hospital of Pittsburgh. UPMC Children's continues to sponsor the event and provide a leading voice in the clinical care and research of pediatric intestinal failure.

This global meeting is designed to bring together pediatric gastroenterologists, surgeons, hepatologists, scientists, and allied health professionals who have dedicated themselves to the care of children with intestinal failure. The premeeting symposia, as well as the main meeting, addressed the latest developments in etiology, pathophysiology, surgical and nonsurgical therapies, quality-of-life, and outcomes-based work in the field.

PIFRS 2020 integrated a medical and surgical dialogue to help build off the dramatic interdisciplinary work that has characterized intestinal failure management. This year's event was co-sponsored by SickKids

Continuing Medical Education Spotlight: Pediatric Liver Transplantation with Patrick McKiernan, MD

UPMC Children's is home to one of the oldest and busiest pediatric liver transplantation programs in the United States, with a decades-long history of clinical advancements and pioneering research in the field of transplant medicine.



In his CME course on "Updates in Pediatric Liver Transplantation," **Patrick McKiernan, MD**, director of pediatric hepatology in the Division of Pediatric Gastroenterology, Hepatology, and Nutrition at UPMC

Children's Hospital of Pittsburgh provides a glimpse into recent advances in liver transplant medicine.

After viewing Dr. McKiernan's lecture, participants will be able to identify the utilization of split liver transplantation in the United States, explain the frequency and significance of allograft histological abnormalities following pediatric liver transplantation, and recognize mortality patterns on the liver transplant waiting list.

View the course and claim CME credit by visiting UPMCPPhysicianResources.com/Pediatrics.

More About Dr. McKiernan

Patrick McKiernan, MD, professor of pediatrics, is the director of pediatric hepatology in the Division of Gastroenterology, Hepatology, and Nutrition at UPMC Children's Hospital of Pittsburgh.

Dr. McKiernan specializes in treating children with inherited metabolic disease and has an interest in developing less invasive therapies to help patients avoid or delay the need for liver transplantation. His research focus covers the clinical aspects of inherited metabolic liver disease, portal hypertension, novel endoscopic techniques, noninvasive markers of hepatic fibrosis, and immunosuppression following liver transplantation. He is actively involved in research on stem cell therapy for metabolic liver diseases.

Dr. McKiernan also has a special interest in tyrosinemia, an inherited disorder caused by an enzyme deficiency that can lead to life-threatening liver and kidney failure. In a study published in 2014, Dr. McKiernan and his colleagues found that children whose tyrosinemia was identified at birth through newborn screening and started on the drug nitisinone developed normally and showed no signs of liver or kidney disease.

Dr. McKiernan completed his medical training at Queens University Belfast, in the United Kingdom. He is an internationally renowned physician in pediatric hepatology and metabolic liver diseases. Dr. McKiernan joined UPMC Children's in 2016 after serving at Birmingham Children's Hospital for 25 years.

Transplant & Regenerative Medicine Centre in Toronto, Ontario, Canada. UPMC Children's Division of Gastroenterology, Hepatology, and Nutrition faculty gave numerous presentations on their research. Participation from faculty included:

Mary Ayres, MD

- Long-term Outcomes of TPN Cholestasis Treatment With Omegaven in Pediatric Intestinal Failure.

Krishnapriya Prathapan, MD

- Megacystis-Microcolon-Intestinal Hypoperistalsis Syndrome: A Case Series With Long Term Follow Up and Prolonged Survival.

Vikram Raghu, MD

- Cost-Effectiveness of Teduglutide in Pediatric Patients With Short Bowel Syndrome With Intestinal Failure: Markov Modeling Using Traditional Cost-Effectiveness Criteria.
- Effect of Adherence on the Cost-Effectiveness of Enteral Iron Supplementation in Children With Intestinal Failure H-14.

- Teduglutide for the Achievement of Enteral Autonomy in Short Bowel Syndrome With Intestinal Failure: A Systematic Review and Meta-Analysis.
- Caregiver Preferences Regarding Decision-Making in Children With Intestinal Failure: A Qualitative Study Focusing on Iron.



Kate Ellery, DO (left)

- Pancreatic Disease in Patients With Intestinal Failure.

Wednesday Sevilla, MD (right)

- Clinical Characteristics and Management of Pediatric Intestinal Failure Patients Diagnosed With D-Lactic Acidosis.

Research Update: Understanding Long-Term Severity of Pediatric Onset IBD in the Presence of Peripheral Blood Eosinophilia

Researchers from the Division of Pediatric Gastroenterology, Hepatology, and Nutrition at UPMC Children's Hospital of Pittsburgh, along with colleagues in the adult Division of Gastroenterology, Hepatology and Nutrition, published new findings in 2020 on the severity of disease in IBD patients diagnosed as children in long-term follow-up as adults.



Division fellow **Krishna Priya M. Prathapan, MD**, was the first author of the study. Internationally respected IBD researcher Sandra C. Kim, MD, director of the Inflammatory

Bowel Disease Center at UPMC Children's, was a senior author on the study and a mentor of Dr. Prathapan.

Published in the journal *Inflammatory Bowel Diseases* in 2020, the new study examined data from a prospective database of IBD patients at UPMC — in two cohorts: patients with adult-onset IBD and adult patients who experienced pediatric-onset IBD. The aim of the research was to determine if an indication of peripheral blood eosinophilia can be used as a biomarker to identify patients at high-risk for a severe disease course that persists into adulthood.

While peripheral eosinophilia can have a variety of causes, such as primary malignancies or infections and allergic reactions, elevated eosinophil production also can be seen in cases of IBD. Chronically elevated eosinophil levels can induce organ damage as a result of inflammatory pathways.

Adult IBD patients identified as having peripheral blood eosinophilia have been shown to have a more severe or aggressive IBD trajectory over the long-term. Pediatric patients diagnosed in childhood with peripheral blood eosinophilia are known to exhibit a more robust clinical manifestation of IBD.

In this study, the researchers examined a dataset consisting of 2,800 adult IBD patients, who were then segmented into pediatric-onset and adult-onset cohorts. Patients records span from 2009 to 2018. 23.4% of the 2,800 patients were identified as having a pediatric-onset disease course. In terms of patients who exhibited peripheral blood eosinophilia at the time of IBD diagnoses, a greater percentage of pediatric-onset patients (34%) exhibited the clinical characteristic versus 26.4% of the adult-onset IBD patients. Adult patients with a pediatric-onset case of IBD and diagnosis of peripheral blood eosinophilia showed a clear difference in several key clinical areas, pointing to a more severe disease course that continued from childhood into adulthood. The patients exhibited higher persistent levels of C reactive protein, elevated levels of erythrocyte sedimentation, and they also showed greater levels of health care utilization and associated increased health care costs.

“It appears as if peripheral blood eosinophilia (PBE), when accompanying a diagnosis of IBD in pediatric patients, portends a higher risk for a more severe case of the disease, the severity of which persists as the patient ages

into adulthood. Using PBE as a prognosticator for those who may be susceptible to aggressive variants of IBD could allow us to take more aggressive actions earlier in an attempt to mitigate disease severity long-term. Through additional research, we may find the risk to be stratified in various ways, but at a minimum, knowing that PBE appears to be a marker for persistent, greater disease severity will help us better screen our patients for potential worse trajectories as they age,” says Dr. Kim.

Full details and findings from the study can be found at the reference below.

Reference

Prathapan KM, Rivers CR, Anderson A, et al. Peripheral Blood Eosinophilia and Long-Term Severity in Pediatric-Onset Inflammatory Bowel Disease. *Inflammatory Bowel Diseases*. 2020; 26(12): 1890-1900.

More About the IBD Center at UPMC Children's Hospital of Pittsburgh

The Inflammatory Bowel Disease (IBD) Center uses a team approach to provide each patient with the most advanced medical care available and compassionate support for the whole family. The IBD Center provides comprehensive, state-of-the-art clinical care to control the symptoms of IBD and to improve the quality of life for children with the disease. Sandra C. Kim, MD, is the director of the IBD Center at UPMC Children's.

Affiliated with the University of Pittsburgh School of Medicine and ranked among the nation's best children's hospitals by *U.S. News & World Report*.



About UPMC Children's Hospital of Pittsburgh

Regionally, nationally, and globally, UPMC Children's Hospital of Pittsburgh is a leader in the treatment of childhood conditions and diseases, a pioneer in the development of new and improved therapies, and a top educator of the next generation of pediatricians and pediatric subspecialists. With generous community support, UPMC Children's Hospital has fulfilled this mission since its founding in 1890. UPMC Children's is recognized consistently for its clinical, research, educational, and advocacy-related accomplishments, including ranking 15th among children's hospitals and schools of medicine in funding for pediatric research provided by the National Institutes of Health (FY2019) and ranking on *U.S. News & World Report's* Honor Roll of America's Best Children's Hospitals (2020-21).