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About IBD
In 2007, investigators from Children’s Hospital of Wisconsin collaborated with providers across the state to show that the annual incidence of IBD among Wisconsin children was 9.5 per 100,000 children; 6.6 per 100,000 for Crohn’s disease and 2.4 per 100,000 for ulcerative colitis. Approximately 19 percent of cases occurred in the first decade of life. Based on this data and similar epidemiologic studies, most pediatric primary care providers in the Midwest will care for children with IBD.

Children with IBD present with myriad symptoms, including:

- Poor growth
- Weight loss
- Perianal/joint symptoms
- Diarrhea
- Bloody stools
- Abdominal pain
- Fevers
- Pubertal delay

We can confirm the diagnosis of IBD through endoscopy of the gastrointestinal tract if a careful history, examination, and/or biochemical and radiographic testing has raised suspicion for this chronic condition. Following endoscopy, additional imaging of the small bowel and skeletal system will help gastroenterologists stage the severity of the disease and assess associated bone health.

Treatment
A new diagnosis of IBD typically causes fear and anxiety for children and their families. This is a challenging process for patients, families and their medical providers, especially if they have limited experience with pediatric IBD. After diagnosis, children with IBD must begin a lifelong effort to understand and control their chronic symptoms.

After discussing the risks and benefits of treatment options with their GI specialist, patients begin individualized therapy plans to manage their symptoms and improve their quality of life. All of these regimens aim to induce and maintain remission with minimal side effects and maximal clinical benefits. There are several treatments options for pediatric IBD that either suppress the immune system (see Table 1) or act locally on the tissue without suppressing the immune system to decrease inflammation (mesalamines). Children with IBD may also respond well to exclusive enteral nutritional therapy, which involves consuming only polymeric formulas that can be taken orally or via a nasogastric tube.

Because of the nature of most pharmacologic treatments for IBD, gastroenterologists closely monitor for medication-associated toxicities, typically hepatotoxicity and bone marrow suppression. This is usually done through serial blood or stool testing, and primary care providers can help by facilitating these periodic tests for their patients close to home. Depending on their treatment regimen, most patients will need surveillance monitoring for related toxicities every 3-12 months.

Health maintenance and monitoring
While pediatric gastroenterologists supervise the diagnostic evaluation and treatment of IBD, the primary care provider’s role of providing a consistent medical home for these patients is essential. Health maintenance is a critical component in pediatric health care for any chronic disease, particularly for children with IBD. It requires a multifaceted effort between specialists and primary care providers to provide patients with the following timely and consistent services:

- Assessment of growth, development and nutrition
- Surveillance of disease activity and treatment toxicity through laboratory testing and screening
- Disease prevention through immunizations
- Health education, anticipatory guidance and counseling

Due to the nature of their disease, children with IBD need particular attention to growth, pubertal development and vaccination against preventable diseases. Children with IBD should have an accurate weight, height and BMI assessment with every clinic visit. Subtle changes in these parameters could indicate disease activity and clinical relapse. These patients require close monitoring for growth failure and obesity, as well as serial assessment of Tanner staging (tailored to the patient’s age and disease status) for appropriate pubertal development. Children with IBD who are in clinical remission but show signs of pubertal delay need timely referral to a pediatric endocrinologist for further evaluation.
Infections are the most common significant adverse event among immunosuppressed patients with IBD, and the risk of serious infection increases with their degree of immunosuppressive therapies. Because many infections are preventable with routine immunizations, vaccines are strongly encouraged and there is no need to deviate from the normal schedule of inactivated vaccines for most children with IBD (see Table 2). At the time of diagnosis, GI specialists will typically confirm immunization status for particular vaccinations and screen for tuberculosis exposure prior to initiating immune suppressive treatments. Primary care providers may be asked to facilitate TB screening with PPD placement and interpretation close to home. GI specialists and primary providers may strive to administer live virus vaccines prior to initiation of immunosuppressive medications, but this may not be feasible based on a patient’s clinical status. Once immunosuppressive treatments have started, children should not receive any live vaccinations (see Table 3).

Due to the chronic and relapsing nature of their disease, children with IBD are at high risk for psychological comorbidities. Primary health providers can take part in important screening and assessment of mental health needs, adjustment concerns and social/academic status changes in these patients. Identifying patients who need pediatric mental health services is vital to their overall well-being. It’s also important to offer adolescents and young adults with IBD anticipatory guidance and counseling against the use of tobacco products. Tobacco products may lead to an increase in IBD flares and increase their overall risk for cancer. Because patients with IBD have a higher risk of colon cancer, it’s imperative to minimize their cancer risk.

Caring for the pediatric patient with IBD requires a close working relationship between primary care providers, pediatric gastroenterologists and other specialists. Optimal care and health maintenance for these children is attainable with close supervision and collaboration within this multidisciplinary team.

**Table 1: Immune-modulating therapies for IBD**

- Corticosteroids
  - Budesonide
  - Prednisone
- Immunosuppressants
  - 6-mercaptopurine
  - Azathioprine
  - Methotrexate
- Biologics
  - Infliximab
  - Adalimumab
  - Certolizumab
  - Natalizumab
  - Vedolizumab

**Table 2: Safe vaccinations while on immune-modulating therapy for IBD**

- Diphtheria
- Tetanus
- Pertussis
- Haemophilus influenzae
- Hepatitis B virus
- Hepatitis A virus
- Pneumococcal
- Human papilloma virus (HPV)
- Meningococcal
- Inactivated Polio
- Attenuated Influenza (intramuscular)

**Table 3: Vaccinations to be avoided while on immune-modulating therapy for IBD**

- Measles, mumps and rubella (MMR)
- Varicella
- Rotavirus
- Intranasal influenza

**References**