

ADVANCES IN IBD

Current Developments in the Treatment of Inflammatory Bowel Disease

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The Transition From Pediatric to Adult Inflammatory Bowel Disease Care



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G&H Why is the transition from pediatric to adult care important in inflammatory bowel disease?

SK Studies in a number of chronic diseases have shown that a well-planned and coordinated transition to adult care improves outcomes. In inflammatory bowel disease (IBD), several studies have shown that the transition from pediatric care to adult care is critical and has the potential to significantly improve outcomes. It is important to recognize that among children and adolescents, Crohn's disease and ulcerative colitis are most commonly diagnosed between 15 and 20 years of age. We also know that approximately one-third of parents and one-quarter of adolescents are apprehensive and anxious about the transition process. This is compounded by the fact that children and adolescents with IBD have a diminished health-related quality of life (HRQOL), and adolescents are particularly susceptible to psychological stress, which further increases their risk for reduced HRQOL. My hope is that by improving the transition process in the field of IBD, we can improve outcomes in this vulnerable patient population.

G&H What are the main differences between pediatric IBD and adult IBD?

SK It is important to remember that children are not small adults. There are significant differences in the presentation and disease course of pediatric-onset IBD vs adult-onset IBD. Among the most notable differences is the fact that children often have more extensive IBD compared with adults. Adults typically have left-sided ulcerative colitis,

whereas children and adolescents present more often with pancolitis. In Crohn's disease, adolescents also have more extensive disease compared to adults, and often present with ileocolonic and upper gastrointestinal tract disease.

In addition, studies have shown that when compared with their adult counterparts, adolescents in particular have more severe and aggressive disease, as demonstrated by higher rates of immunomodulator and biologic use as well as higher rates of hospitalization. All of these findings are compounded by the fact that adolescents typically have a higher rate of missed appointments compared with adults, pointing to the need for different approaches of care for this patient population.

G&H How does pediatric or adolescent care differ from adult care in IBD?

SK There are many differences between pediatric or adolescent IBD care and adult IBD care. Management styles and approaches differ; adult visits are often shorter and patient-focused, whereas pediatric visits are often longer and family-focused. Therapies and clinical trials available to adult patients may not be available or as accessible for children and adolescents. Procedure-related care also differs; children and adolescents typically have full sedation and anesthesia during procedures, whereas adults usually have conscious sedation and are often awake during procedures. There are also significant differences in the functioning and feel of an adult hospital vs a pediatric hospital. All of these differences have the potential to cause anxiety for the transitioning adolescent/young adult.

G&H What knowledge and skill sets are needed for IBD patients to transition to adult care?

SK Health care providers expect that adolescents and young adults have a knowledge and awareness of their disease (eg, they understand their diagnosis, the extent of their disease, and past surgeries and complications). Providers also expect them to have mastered self-management skills so that for the most part, they can manage their IBD independently. For example, adolescents and young adults should know their medications (including the name, doses, and frequency) and should be able to call when they need refills or are experiencing a potential side effect. They also must know how to contact their provider to make appointments or call when they are sick, and know what type of insurance they have and how to contact their insurance provider. Although there are no consensus guidelines or universally accepted criteria for transition to adult IBD care, there are several different transition checklists that are available that can help providers determine transition readiness in adolescent and young adult patients.

G&H What are the most significant barriers to successful transition of IBD care?

SK According to several recent studies, some of the most common barriers are related to patient readiness and maturity. Other barriers include parent or physician reluctance to transfer care. Not surprisingly, comorbidities or development and cognitive limitations can also be a significant barrier to transition to an adult provider. There may also be barriers around the identification of an appropriate provider for a patient, particularly if he or she has limited options from his or her insurance plan or health care system.

G&H When and how should the transition of care start in terms of patient and provider tasks?

SK Many providers, patients, and families do not realize that transition is not simply the transfer of care from one provider to another, but a process through which an adolescent gains the education and self-management skills to become an adult who can successfully manage his or her chronic disease. Some groups use an arbitrary or hospital-based cutoff between age 18 and 21 years. This age cutoff varies, particularly because there are significant differences in health care systems and institutional practices worldwide. Other important factors that determine age at the transfer of care include individual practices, the maturity of the patient, and family/parent readiness.

Although general recommendations for transition have been published by the North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition (NASPGHAN) as well as in a joint report from the American Academy of Pediatrics, the American Academy of Family Physicians, the American College of Physicians, and the Transitions Clinical Report Authoring Group, there is currently no consensus regarding the timing of transition or which approaches, tools, and standards are the most effective. According to these general recommendations, transition discussions should be initiated far in advance of the actual transfer of care to an adult IBD provider. Pediatric IBD providers should start to introduce concepts of disease knowledge and self-management in patients as young as 12 years of age. At this point, pediatric patients are not ready to transfer care, but they should begin to learn more about their disease, diagnosis, and medications. Over the next several years, they should develop a concrete understanding of their diagnosis, medical history, and medications, and they should take on increasing responsibility for their IBD management. A strong foundation of disease knowledge and self-management skills can enable adolescents and young adults to have a successful transition process, thereby decreasing the risk of medication nonadherence, poor follow-up, and disease relapse.

G&H Are any other recommendations or guidelines available for pediatric or adult gastroenterologists on how to best transition patients into adult IBD care?

SK As mentioned, NASPGHAN and the American Academy of Pediatrics, the American Academy of Family Physicians, the American College of Physicians, and the Transitions Clinical Report Authoring Group have all recommended standards for establishing a transition process to ensure that patients are not lost to follow-up and have the skills they need to become independent adults who manage their own health care. However, in IBD, specific guidelines and best practice models are lacking. Transition in IBD is quite variable and often reflects individual practitioner approaches and health care system-based practices. For example, if a patient is part of a medical system that has both a pediatric and adult IBD practice, the transition and transfer are much easier to navigate and the providers can more easily establish a defined process. In health care systems where the adult and pediatric practices are not linked, coordinating transition and transfer will require more planning. Regardless of the system, pediatric and adult IBD providers should work to establish relationships and processes to facilitate transition and transfer of care.

G&H What role does medication adherence play in transitioning patients?

SK We know that medication adherence is an important factor in improving outcomes in IBD regardless of age. Studies have shown that young children whose medication is monitored and managed by their parents have better adherence. Adherence rates drop in adolescent and young adult populations, increasing the risk for poor outcomes and disease-related complications. Unfortunately, no specific adherence guidelines are available. However, by addressing issues around adherence, providers may be able to promote adherence and help adolescents and young adults stay healthy and out of the hospital.

G&H What resources and tools are available to adolescents during the transition process?

SK The Crohn's and Colitis Foundation of America (CCFA) has several useful tools for patients to facilitate the transition process. The CCFA has an online database of IBD providers across the country, which can facilitate transfer of care for patients if they are moving or going away to college or trade school. In addition, the CCFA has developed the GI Buddy application for smartphones, which can be useful for tracking symptoms, diet, and medications while promoting disease awareness and community involvement with others who have IBD. The MyIBD application that was developed by The Hospital for Sick Children (SickKids) in Toronto, Canada is another useful and easy application for patients to track symptoms, medication adherence, and medical history. I ask my patients to download one or both of these free applications while they are in clinic and to use them if they are starting to flare or if they are having trouble with adherence.

In general, smartphones are a great tool for promoting self-management. Patients can use the phone to make notes or compile questions about their disease or to take pictures of their medication bottles if they have trouble remembering medication names and doses. Many pharmacies now also have auto-refill applications that patients can use so that they do not have to call in prescription refills. These applications also have adherence tools to help patients remember when to take their medicine or when to pick up refills.

A number of websites have been developed to promote engagement of adolescents as well as transition knowledge and awareness. Useful websites such as IBDU.org have been specifically designed for adolescents with IBD as they move toward independence. Other websites such as GotTransition.org have information and resources for patients, families, and providers about the transition process.

In addition, several groups across the United States as well as abroad are developing transition tools targeted at adherence, self-management, and engagement of adolescents and young adults using technology-based platforms.

G&H What is the role of parents and caregivers in the transition of care?

SK Parents and caregivers should be actively involved in their adolescent's care to help facilitate transition. Parents need to foster disease awareness and encourage their children to take increasing responsibility for disease management. In addition, parents and caregivers can serve as positive role models for self-management.

Many parents have significant concerns about the transition to adult IBD care and can be quite attached to their child's pediatric IBD provider. For parents, there can be significant apprehension and anxiety about the transition process, which can be mitigated by education, communication, and thoughtful planning around the transition process. Hopefully, by creating open dialogues around the transition process that are initiated far before the actual transfer of care, parents will be actively engaged and supportive. As such, pediatric IBD providers need to make sure that not only are their adolescent patients ready for transfer to adult care but that the parents and caregivers are ready as well. Just like any other major life transition, making sure that everything is in place improves the chances of success. The presence of a parent or caregiver who is supportive and who encourages the adolescent to take responsibility for his or her own disease management is fundamental for ensuring success.

G&H Are there any other considerations that should be taken into account when managing IBD patients transitioning to adult care?

SK It is important for providers to keep in mind that IBD can negatively affect a patient's educational experience and success, which can in turn have a significant effect on the transition process. Adolescents often have poorer school function and more absences than healthy children, which can alter their educational path and trajectory. It is important for both pediatric and adult IBD providers to understand that many adolescents and children with IBD miss days or even months of school due to their illness and, as a result, may need to attend summer school, take a leave of absence from school, be homeschooled, delay college, or go to college closer to home. These educational factors need to be addressed as part of the transition process as well.

Another factor that both providers and parents need to be aware of is that adolescents and young adults are

particularly vulnerable to psychological stress and may also be suffering from anxiety or depression. Symptoms such as fatigue, poor sleep, changes in appetite, and even abdominal pain can be signs of active IBD, but also can be due to anxiety and depression. In the latter case, patients should be referred to a therapist or psychiatrist for further evaluation and treatment. Providers should make sure that they are not just meeting the medical needs of their patients, but that they are aware of how the disease negatively impacts the educational experience and psychosocial development of their patients as well.

G&H Do most medical centers have IBD transition programs or clinics?

SK IBD transition programs and clinics are still a relatively unique feature in most medical centers. There are only a handful of transition clinics and programs that have been established around the country and abroad. As the availability of transition programs and clinics grows, they will become an integral part of IBD care and will facilitate the care of this vulnerable population. These programs can also foster transition-related research, which will provide data about the epidemiology and biology of adolescents and young adults with IBD. In addition, research can help identify different approaches to overcome barriers in the transition and transfer process and aid in the development of tools to promote health and self-management. Through these combined research and clinical efforts, we will be able to develop consensus

guidelines and best practices to facilitate successful transition of care, and ultimately will improve outcomes in adolescents and young adults with IBD.

Dr Kahn has served as a consultant to AbbVie.

Suggested Reading

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