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Introduction

Transition of care is emerging as an increasingly important area of care in patients with chronic conditions including inflammatory bowel diseases (IBD). Transition from pediatric to adult care is not simply a transfer of patient care from one provider to another. It is a dynamic process defined as the purposeful planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health-care systems [1]. Education, communication, and preparation promote self-management skills, confidence, and independence, which help ensure a successful transition. Effective transition requires a multidisciplinary and coordinated approach to ensure successful “graduation” which is marked by independence, effective self-management, and establishment of care with an adult gastroenterologist and adult medical care team. Several medical societies and groups have issued consensus statements regarding the need for coordinated and well-planned transition for adolescents and young adults with chronic medical conditions [2, 3], [4, 5]. According to the American Academy of Pediatrics (AAP), transition should address the following: (1) Ensure that all young people with special health-care needs have an identified health-care professional who attends to the unique challenges of transition and assumes responsibility for current health care, care coordination, and future health-care planning. (2) Identify the core knowledge and skills required to provide developmentally appropriate health-care transition services to young

people with special health-care needs and make them part of training and certification requirements for primary care residents and physicians in practice. (3) Prepare and maintain an up-to-date medical summary that is portable and accessible. (4) Create a written health-care transition plan by age 14 together with the young adult and family. At a minimum, this plan should include what services need to be provided, who will provide them, and how they will be financed. This plan should be reviewed and updated annually and whenever there is a transfer of care. (5) Apply the same guidelines for primary and preventive care for all adolescents and young adults, including those with special health-care needs, recognizing that young people with special health-care needs may require more resources and services than other young people to optimize their health. (6) Ensure affordable, continuous health insurance coverage for all young people with special health-care needs throughout adolescence and adulthood [3].

Similarly, the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) and the Crohn’s and Colitis Foundation of America (CCFA) have issued specific statements regarding the transition of care for adolescents with IBD [6, 7]. NASPGHAN recommendations for the practitioner suggest the following: (1) The pediatric gastroenterologist should begin seeing adolescent IBD patients without their parents to build a relationship promoting independence. (2) Introduce the patient and family to the concept and benefits of transition. (3) Identify a skilled gastroenterologist who cares for young adults and recognizes the different set of expectations that young adults with childhood-onset IBD have versus those recently diagnosed with IBD. (4) Prepare a detailed medical letter and brief medical summary for the new adult gastroenterologist. (5) Recognition that the timing of transition requires flexibility due to individual special circumstances. These guidelines addressed a number of issues that adolescents with IBD encounter, including the process of moving from parental oversight to independence and self-reliance and transferring care from the nurturing medical care approach commonly seen in pediatric care practices. Other

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factors that should be incorporated into the transition process include the need of both parents/guardians and pediatric health-care providers (including physicians, nurses, and many other health-care providers) to relinquish caregiver roles of young adults living with a chronic illness and to facilitate successful transfer of care to an adult subspecialist.

Despite these useful guidelines, there is still no “gold standard” or defined best practices for transition of care in IBD, highlighting the need for more research on this vulnerable population [8]. In this chapter, we will outline the recommendations for transition of care in IBD, unique features of the adolescent IBD population, barriers to transition of care, and approaches, skills, and tools that can facilitate a successful transition to adult IBD care.

Background

Although there is growing emphasis on transition of care for adolescents with chronic medical conditions, there is a relative lack of data about which approaches and models work best in adolescents and young adults (AYA) with IBD [9]. This gap in our knowledge is due in part to a dearth of research on this topic, as well as the high degree of variability between health-care systems on a regional, national, and international level, therefore limiting the generalizability of a given approach. Despite these limitations, transition of care for young adults with IBD is important for several reasons. First, up to one-third of parents and one-fourth of teens are apprehensive about transition to an adult provider [10]. Second, youth with IBD have diminished health-related quality of life (HRQOL) [11] that can dramatically increase during adolescence when they are especially vulnerable to psychological stress [12]. HRQOL is a vital aspect of patient care, patient-physician communication, and shared decision-making. Finally, a well-planned and coordinated transition to adult care has been shown to improve outcomes in patients with other chronic disease [13]. Factors associated with successful health-care transition include starting the process early, having family members and health-care providers foster personal and medical independence, and confirming that the young adult verbalizes the desire to function in the adult medical world [14].

The ultimate goal is a prepared, proactive health-care team and an informed, active patient – a concept particularly applicable to patients with IBD. Evidence supports the idea that pediatric and adult-oriented medical practices represent two different medical subcultures. If young adults and family members are not well prepared for participation in the adult health-care system, they will have trouble with this transition and may not receive the care they need [14].

Challenges and Barriers to Transition for Adolescent IBD Patients

Researchers have begun to identify specific barriers to transition in teens and young adults with IBD. These barriers include differences in pediatric-onset versus adult-onset IBD, differences between pediatric and adult care, psychosocial factors, treatment adherence and poorly developed self-management skills, attachment to pediatric providers, individual maturity, and readiness for transition. Recently, two different groups found that patient and parent/guardian attachment to pediatric providers was among the most significant barriers to transition [15, 16]. Not surprisingly, Bensen et al. also found that patients with emotional and cognitive delay faced additional challenges in the transition process [15].

Differences between pediatric- or adolescent-onset IBD and adult IBD can also have a significant impact on the transition process. Although pediatric- and adolescent-onset IBD is common, occurring in roughly 20–30% of all cases [17, 18], there are significant differences in pediatric and adolescent disease presentation and severity; most notably, pediatric/adolescent IBD is more aggressive and extensive [19, 20, 21]. A recent study by Van Limbergen and colleagues found patients with pediatric-onset disease were almost twice as likely to have extensive ulcerative colitis (UC) compared to those with adult-onset disease. Similarly, among those children with Crohn’s disease, 40% had extensive disease compared to 3% of their adult counterparts. Surgery within 10 years of diagnosis was twice as common in pediatric-onset UC. Although there was less surgery in pediatric-onset CD, more than one-third required surgical intervention within 10 years of diagnosis [21].

Goodhand et al. have demonstrated that compared to adults, teens have more severe disease. Adolescents were more likely to be on azathioprine (46% vs. 17%, $P < 0.0001$) or infliximab (20% vs. 8%, $P < 0.05$). Furthermore, teens were more likely to require hospitalization (46% vs. 14%, $P < 0.0001$). This is further complicated by the fact that teens were significantly more likely to miss medical appointments than adults (median appointments missed: adolescents 20% vs. adults 0%; $P < 0.0001$). The authors concluded that earlier-onset IBD is more complex, and, therefore, specific adolescent transitioning clinics should be established [19]. This highlights the need for additional research to better understand outcomes and the natural history of IBD in this unique group that spans both the pediatric and adult populations.

Treatment adherence and self-management are key skills that teens must master during the transition process but are often difficult for AYA [22, 23, 24]. Several studies have identified barriers to adherence in adolescents that include the following: forgetting to take medications [25],

lack of time, feeling well, medication side effects [26], and therapeutic regimen complexity [27]. These barriers can be further exacerbated by the patients' underlying anxiety and depression [25]. In addition to adherence, teens must develop a wide range of self-management skills often lacking in teens with IBD prior to "graduation" from their pediatric provider. Fishman et al. surveyed teenagers aged 16–18 years and found that only 43% confidently knew their medication name and dose and even fewer knew about important side effects. In addition AYA relied heavily on parents to schedule appointments (85%), request refills (75%), and contact providers between visits (74%) [22]. In a follow-up study, Fishman and colleagues surveyed 294 youth, 10 years and older, and found that although 95% could name their medication, just over half knew the correct dose and less than one-third could report a single major side effect [28]. Although self-management skills and independence have been shown to increase with age, they do not necessarily correlate with disease duration, reinforcing the complex nature of teaching skills to teens with IBD [24].

Differences in approaches to pediatric and adult medical care can have a profound impact on the transition process as well. Hait and colleagues point out that pediatric care tends to be multidisciplinary and family focused and requires parental direction and consent. On the other hand, a single physician often provides care in adult medicine; the relationship involves shared decision-making exclusively between the patient and provider rather than the entire family. The adult health-care clinic visit is patient focused, and the provider expects the patient to be autonomous and independent [29].

A survey of adult gastroenterologists in 2009 reported that 51% had received an inadequate medical history from pediatric providers, 55% of young adults with IBD demonstrated deficits in knowledge of their medical history, and 69% did not know their medication regimens [29]. The authors suggested that educating the young adult IBD patient is essential but not a substitute for delivering an accurate medical history to the adult provider. In contrast to this survey of adult gastroenterologists, a French survey of 48 young patients with IBD (and their parents) who had transitioned from pediatric to adult care revealed that the majority (85% of patients and 74% of parents) felt they were ready for transition to adult care [10]. Only 22% of patients and 32% of parents were apprehensive of the process. Of the 57% that attended a joint medical visit with the pediatric and adult providers, all considered it beneficial for transmitting records and most (93% of patients and 100% of parents) considered it beneficial for building confidence in the new gastroenterologist, highlighting the benefit and need for more transition clinics.

Transition Steps

The appropriate age to begin teaching these skill sets will vary with each patient's level of maturity and interest. However, starting by age 12–14 years gives the patient and family adequate time for the process and allows each patient the opportunity to gradually assume more responsibility for taking care of their own unique problems. The skill sets involve accruing knowledge (education), developing self-management skills based on that knowledge (focus on independence), and understanding the mutual impact of inflammatory bowel disease and lifestyle decisions on future health and well-being. This process should be tailored to the individual patient based on their needs.

NASPGHAN, the National Alliance to Advance Adolescent Health, and others have made useful planning and readiness checklists to help facilitate the successful transition to adult care (GotTransition.org [30]; [31]; NASPGHAN [32]).

Overview of the Transition Process

A number of tools, checklists, and planners to facilitate the transition process and transfer of care are described in Table 60.1. It is important to remember that the process should be tailored to the individual patient and family and may need to be adapted according to factors such as insurance, location, and post-high school plans.

Patients (Age 12–14)

At this age, the patients should be introduced and educated on the idea of transition and begin steps to prepare themselves toward this goal. There are two skill sets that should be attained for this age group.

Skill set 1 Knowledge related to their illness: This first step is designed to help patients learn about their specific disease, either Crohn's disease or ulcerative colitis. The patient should be able to articulate that they have IBD, including both gastrointestinal and extraintestinal symptoms, and recognize when they are having a flare and what might be precipitating the flare (diet, stress, other medications, etc.) and when they should visit their physician. The child should be able to express the impact of his/her disease on daily functioning at school, socially, and at home. Providing handouts with these key points and specific age-appropriate websites can help patients develop resources for ongoing education and new information (e.g., <http://www.cdfa.org/kids-teens>).

Skill set 2 Knowledge related to medications: This step includes information about specific medications they are

Table 60.1 Transition resources and tools

<i>Educational resources and transition guidelines for providers</i>	
“A case-based monograph focusing on IBD: Improving health supervision in pediatric and young adult patients with IBD” (NASPGHAN)	
“Educate, communicate, anticipate: Practical recommendations for transitioning adolescents with IBD to adult health care” [31]	
Transition of the patient with inflammatory bowel disease from pediatric to adult care: Recommendations of the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition” [6]	
“Transitioning the adolescent inflammatory bowel disease patient: Guidelines for the adult and pediatric gastroenterologist” [7]	
<i>Transition readiness assessment and tools</i>	
<i>For patients</i>	
Patient checklist for preparing to transition from a pediatric to adult care practitioner [33]	
“Preparing to transition from a pediatric to adult care practitioner”: http://www.gikids.org/files/documents/resources/IBD-TransitionTeenIBD.pdf	
<i>For providers</i>	
Healthcare provider checklist for transitioning a patient with IBD from pediatric to adult care [32]	
“Transitioning a patient with IBD from pediatric to adult care”: http://www.gikids.org/files/documents/resources/Checklist_ONLYHealthcareProdiver_TransitionfromPedtoAdult.pdf	
TRxANSITION scale and STARx transition readiness questionnaire [34, 35]	
<i>Health passports, self-management tools, and symptom trackers</i>	
GI Buddy (symptom tracker): http://www.ibdetermined.org/Tracker.aspx	
Good 2 Go Transition Program – MyHealth Passport: https://www.sickkids.ca/myhealthpassport/	
Gut Check app (symptom tracker): https://www.gutcheckapp.com	
myIBD (symptom tracker): http://www.sickkids.ca/IBDacademy/IBD-Mobile-App/	
<i>Resources for adolescents and parents</i>	
American Academy of Pediatrics: “How to help your teen transition to adult health care”: http://www.healthychildren.org/English/family-life/health-management/Pages/How-to-Help-Your-Teen-Transition-to-Adult-Health-Care-Video.aspx	
CCFA Campus Connection: http://www.cdfa.org/campus-connection/	
CCFA IBDetermined: http://www.ibdetermined.org/	
IBD University (IBD U): http://www.ibdu.org/	
ImproveCareNow: https://improvecarenow.org	
Just Like Me: http://www.justlikemeibd.org	
<i>Transition advocacy and support for patients, parents, and providers</i>	
“Got Transition/Center for Health Care Transition”: http://gottransition.org/	
The Society of Adolescent Health and Medicine: http://www.adolescenthealth.org/Home.aspx	

taking (name, dose, why they are taking the medication, timing of each dose, possible side effects) and, finally, establishing a plan to take medications on their own without being reminded. This step is also crucial as a first step in preventing the lapses in adherence to medication, which occurs quite frequently at this age and throughout adolescence [23]. Bell has also noted that adolescent risk taking, magical thinking, and denial can all contribute to poor treatment adherence [36]. Patient education and problem-solving skills training are key approaches to overcome these issues, as is having a positive relationship with health-care providers and family members ([37]; [38]). Because increased authority from parents and professionals, overprotection, and sick role in teens with chronic disease may lead to learned dependency ([36]), this is a good time to begin to promote independence by setting a date when the patient will visit with their provider alone, starting by performing the physical exam without the parents/guardians in the room.

Parents/Family (Age 12–14)

Reiss and colleagues have found that parents often feel excluded when their child transitions to an adult provider, especially after they have dedicated many years of supporting and being involved in their children’s health care [14]. Parents may also have concerns about “letting go,” and family resistance can be a major barrier to successful transition. In order to prevent these negative feelings, parents should also be informed and educated regarding the eventual need for transition – the process of “letting go,” so that their child can function independently as they leave home for work or college. The main role of the family at this time is to support the child through the disease symptoms and exacerbations and to provide a comfortable and protective atmosphere for this transitioning period. Since parents are actively involved in the daily care of their young adult children, they are the key personnel to reinforce the list of items needed at each visit for a successful transition. They should be notified that future clinic visits might include an established period of

time for the young adult patient to meet with the health-care provider on their own. As part of the process, the parents can be provided the opportunity and a primary role in making their child independent through each step, as they help educate their son/daughter on crucial topic areas including insurance coverage, refilling medications, and scheduling appointments independently. Another important role for parents is to observe and confirm to the pediatric GI team that their child is making progress mastering the skills required for independence prior to the transfer of their care to adult providers.

Pediatric Team (Age 12–14)

The pediatric team often includes the pediatric gastroenterologist, nurse, psychologist, dietitian, and other pediatric subspecialists involved in managing the patient's care. The pediatric gastroenterologist, who is usually the primary provider, will establish the parameters for the support staff in promoting this transition period. Teaching of transition skills (those chosen as most important by each practice or institution) may be directed by a nurse, nurse practitioner, or the gastroenterologist, depending on staffing and availability. It is critically important for the physician to convey the importance of the process to the patient and family so that they understand, recognize, and accept the benefits of increasing the patient's self-management of their disease.

The pediatric gastroenterologist should address the concept of independent clinic visits for the patient with the family. This should start by including the parents for the initial portion of the visit, followed by the gastroenterologist performing the physical exam without parents/guardians in the examination room. Topics the pediatric gastroenterologist should address include information and guidance regarding drugs, alcohol, dating/sexuality, and health maintenance issues (i.e., diet, exercise). It is also important to address the medication adherence and compliance, which can impact future health and can be a significant issue in young adults with IBD [39]. Furthermore, potential psychological issues should be screened and identified so that referrals can be placed with mental health professionals. This helps address anxiety disorder/depression which, when left untreated, can hinder the transition process and successful attainment of the necessary self-management skills [25].

Focus on Independence

Patients (Age 14–17)

Patients in this age group should acquire the following two major skill sets that focus on increasing their independence:

Skill set 3 Knowledge related to procedures and tests: This would include laboratory tests, diagnostic imaging, and

endoscopic procedures used in managing the patient with IBD. The goal is for patients to not only be comfortable with the different tests and procedures but also to recognize their importance and purpose in managing their disease long term.

Skill set 4 Basic medical knowledge: This step emphasizes basic medical knowledge that all patients should know, regardless of the presence or absence of a chronic illness. This includes knowing how to measure their weight, take their temperature, and read a thermometer. It also includes learning or knowing where to find telephone numbers and locations for their health-care provider, their clinic, and the hospital. They should be able to articulate their medical history and to identify names of community-based social support groups and organizations (e.g., Crohn's and Colitis Foundation of America, CCFA). Patients should be able to articulate the medical risk of nonadherence, and they should understand the impact of illicit drugs and alcohol on their illness as well as the interactions with their ongoing medications. This may take a little time in the office demonstrating some of these skills, and it will require some work from the family to help set up their own system for reinforcing this information. In addition, patients might be asked to prepare questions ahead of time for the doctor and nurse or dietitian.

The patients should begin filling their own prescriptions, scheduling their own appointments, and keeping medical information and insurance information. The patient should also develop a method of tracking symptoms and issues related to their IBD. This makes their clinic visit with their physician effective and centered on the patient while helping the patient to demonstrate the ability to be more independent with their health care. During the visit, the patient can privately address questions they have regarding adolescent issues and discuss future plans upon the completion of high school. Patients should be educated, however, that the parent or guardian must legally be informed about the overall condition and high-risk behaviors more common in teens and young adults that could seriously affect their disease.

Parents (Age 14–17)

Since the main focus at this age is to promote independence, the family/parents/guardians should teach their child the intricacies of medical care as if they were out on their own. Examples include the following: maintaining a current medication list, filling and refilling prescriptions, and scheduling clinic appointments. They can provide guidance on organizing medical information in a dynamic fashion, which is crucial. Parents should also provide all information regarding insurance (insurance card, relevant contact numbers). Most importantly, the parents should continue to reinforce the skill

sets that the patients need at this developmental stage outside routine clinic visits and to update the pediatric health-care team on their child's progress during the transitioning process.

Pediatric Team (Age 14–17)

The pediatric gastroenterologist as well as the pediatric health-care team should start and continue to focus on the patient instead of the parents or guardians when providing explanations and when obtaining the history. This includes making sure part of the visit occurs without parents in the room and allowing the patient to decide on the appropriate timing. This allows the physician to directly interact with the patient and is essential in the progression toward independence the young adult needs prior to transfer of care. The physician should explain to the patient what the parent or guardian must legally be informed about regarding their condition. During this process, the physician and patient should develop goals and timelines for specific skills required during the transitioning process (i.e., filling prescriptions and scheduling appointments). These visits should also address sensitive topics including drug and alcohol usage, as well as the impact of disease on sexuality and fertility. Future work and school timelines need to be considered during this transitioning process to optimize effective timing for the transfer of care as well as identifying future adult providers. Psychosocial monitoring including screens for anxiety, depression, and quality of life as well as transition readiness is recommended given the impact of ongoing psychosocial comorbidities on medication adherence and effective transfer of care.

Self-Management: Health and Lifestyles

Patients (Age 17–18)

This is the crucial period before the actual transfer of care to an adult provider. The two skill sets they need at this stage include the following:

Skill set 5 General self-management skills: Skills attained in this set put the knowledge acquired in the other skill sets to practical use and help patients move toward independence. The patient should receive an outline or plan for managing their disease, especially as they may leave home for work or school. They should be familiar with their medications and their medical history, learn to call in their own prescriptions, make their own clinic appointments, begin to collect copies of their health records/medical summary for work/school, and learn about adult providers, based on the location of where they will be in the near future (adult gastroenterologists near their new home/school/work). They should carry an insurance card and understand the concept of medical

insurance as well as more specific details including eligibility requirements, co-pays, and other potential resources for coverage such as Social Security Disability Insurance (SSDI).

Skill set 6 Health and lifestyle decisions: The acquisition of skills from this skill set includes the patient gaining a general understanding of the importance of health maintenance and the potential interplay of their disease and lifestyle decisions. General knowledge includes the beneficial effects of exercise and an appropriate diet as well as the adverse effects of drugs, alcohol, and smoking. They should know the specific impact of disease activity on fertility and sexuality and the consequences of nonadherence. Patients should understand that at age 18, they are considered autonomous adults in terms of their health care; they have the right to make their own health choices, and their health information cannot be shared with others including parents or guardians without permission.

Parents (Age 17–18)

Several studies in other chronic diseases have shown that parents may feel relegated to the sidelines as their children transfer to adult care. If the transition process has been implemented from an earlier age, and the parents have been educated, this should not occur. Parents can have concerns about their sons' or daughters' limitations in self-advocacy or cognitive function, and thus, can be justifiably worried about their ability to cope. These issues should be addressed at this visit, so everyone involved (the parents, the pediatric team, and the patient) in conjunction can find a solution to overcome any obstacles. Ultimately, at this age, the parents should show less and less responsibility for the patient's care as the patient assumes more responsibility. This is the time where the parents need to officially practice letting go. They should encourage their child to go to their follow-up visit alone or at least allow them to visit with the doctor alone for at least part of their visit. To address concerns most parents could have of missing critical information, it is helpful to address a list of questions addressing their concerns and to have the young adult patient ask the questions (or let the parents ask separately after the visit but generally with the patient present). They should also understand that once their child turns 18, HIPAA regulations come into play, and the parent cannot obtain medical information unless the patient provides approval. This becomes an issue as parents often call the adult clinic asking for results and medication refills, appointments, and management decisions/plans.

Pediatric Team (Age 17–18)

At this stage, the pediatric team should prepare for the final clinic visits prior to transfer of care. The pediatric health-care

Table 60.2 Medical summary letter

Medical summary letter for transitioning IBD patients
Disease information: date of diagnosis, location, severity
Findings: labs, endoscopy, histology, radiology results, and dates
Medical therapies: dose, duration, adverse reactions, reasons for discontinuation
Surgical history
Psychosocial, developmental, and educational issues

Adapted from Hait et al. [31]

team should remind the patient and the parents that at age 18, patients have the right to make their own decisions. The pediatric team should help identify potential adult IBD providers and encourage and facilitate an initial visit. Ideally, a transition clinic setup is optimal; however, few clinical centers/hospitals have one. A return visit after they have seen the adult provider may be helpful to discuss their experience and troubleshoot any remaining concerns. Plans for insurance coverage should be discussed with the patient and parents. Identifying any insurance coverage is important as this may impact who they may be able to see as they transition. The patient should be provided a summary of their medical history for school or work and obtain any consent for health information in order to provide to the new adult gastroenterologist. In addition, the team should complete a medical summary of the patient to provide to the adult provider. Hait and colleagues have suggested the following to be included in this letter (Table 60.2).

Before the last visit, the provider should confirm that psychosocial needs are addressed to ease the transitioning process as well as any other potential barriers to transfer of care, including financial issues, attitudes, access, and family resistance. The medical team should discuss differences in the cultures of pediatric and adult medicine. It is important whenever possible to refer the patient in times of disease quiescence and social stability when the transition is most likely to be successful. This may occur at different ages for various patients. For those who attend college, the transfer may be after graduation and after a job is secured or graduate education has begun. For those who choose not to attend college, the transfer of care should occur when housing and employment arrangements are stabilized.

Adult Team (Age 18+)

The adult gastroenterologist's role in the early transition process is minimal as the patient only arrives to them at the end of this process around the age of 18; however, his/her role in accepting and facilitating transfer of care is a key. In general, the adult gastroenterologist should only accept the transfer after he or she has been given an adequate medical history of this patient from the pediatric provider. This will help provide the most optimal care as medications, and prior medical and surgical history will be important in ongoing medical

care. Since the adult gastroenterologist can potentially have an even longer role in the patient's chronic care, the transition is crucial in establishing a physician-patient relationship that fosters independence as well as confidence, trust, and communication in both parties.

The adult gastroenterologist's role is to continue to foster this independence with the patient. The patient should continue to be the main focus and should be seen independently from the parents, especially if over-concerned parents tend to drive the visit interactions. At this time, legal implications of health care can also play a role. The patient is solely responsible for their medical information. It will be up to him or her to decide if, and to what extent, the parents should be involved. HIPAA regulations will come into play as parents, once used to obtaining and providing information, now legally do not have a role without the patient's consent. The adult gastroenterologist and the adult care team (nurses, medical assistants) should be aware of this when parents of transitioned patients call for information. However, if the transition process is successful, the patients will contact the office themselves for medical information.

The adult gastroenterologist should acknowledge the parents and work jointly to continue to allow for the patient to remain independent and communicate any issues they have at the first visit. There should be mutual understanding of everyone's role. Since the parents have been a key player in their child's chronic illness, it is understandable that the parents will have concerns and questions, as well as some resistance toward the transition. However, with the understanding and acknowledgement that the adult gastroenterologist's goal is to provide optimal care for the patient, then the family, patient, and physician can work together toward the same goals.

The adult gastroenterologist should confirm that the patient has established a relationship with an adult primary care physician, especially if the patient has been seeing a pediatrician for their general health care. Specialists often take on the role of "generalist" due to their frequent interaction related to IBD visits. However, obtaining a primary care provider (PCP) is important to provide optimal care regarding other illnesses such as general health care, immunizations, and screening for other diseases such as breast and prostate cancer and for preventive care for other diseases such as hyperlipidemia, diabetes, and hypertension.

The adult team should confirm that all relevant medical records are obtained, including any outstanding information that may still be needed. This may warrant a phone conversation with the pediatric health-care providers to include specific social history, developmental issues, and family dynamics that may not have been fully explained in the records. The importance of adherence to therapy should continue to be addressed at this time as well as any parental concerns. The adult provider should anticipate and answer any

questions about smoking, alcohol, substance abuse, and sexuality as well as the psychosocial impacts their disease may have. They should also educate the patient regarding the adult chronic care model.

Monitoring the Process

Some system should be established to monitor both the teaching of the above skills and what has been learned and retained. This might be done through pop-up messages on an electronic medical record, where objectives and follow-up learning must be recorded by date, or a special form could be kept in the patient's chart to check off each set once taught and then mastered. The patient could also be given a copy of this checklist so they know what the entire skill set contains. A member of the health-care team should be dedicated to documenting this process to ensure patients are making progress in becoming independent. Having set questions at follow-up visits to document what has been learned is also important. Typical questions that patients might be expected to answer at a follow-up visit are as follows: (1) Can you describe your disease? (2) What are your symptoms of IBD? (3) What situations should you avoid? (4) When should you call or see the doctor? (5) What is your doctor's or nurse's phone number? (6) Did you make this appointment? (7) Have you called in one of your prescriptions for refill? (8) What health records have you collected (i.e. endoscopy reports; laboratory test results)? (9) Who is your insurance carrier? Before final transition, time should be set up to do a final review of their competence in all areas, and then when the patient is ready, preparations can be made to transition care to an adult provider. At this point, the patient should already be taking care of his or her health issues, and a successful outcome for transition is likely.

Conclusion

The transition process can be a challenging time period for adolescents living with IBD as they move toward adulthood. However, a successful transition can be implemented if steps are taken early in the process with the combined effort from the patient, the parents/guardians, and the pediatric gastroenterology team. The key is to provide sufficient and early training around the process so that the young adult patient, their family, and their providers can progress through the process together ensuring adequate time to adapt and prepare for a successful transition and graduation to adult gastroenterology care. A dynamic and supportive process will help young adult IBD patients effectively self-manage their health-care needs and become independent young adults who can manage their own complex medical needs.

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