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Transitioning the Adolescent Inflammatory Bowel Disease Patient: Guidelines for the Adult and Pediatric Gastroenterologist

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Abstract

Twenty percent of inflammatory bowel disease (IBD) patients present in the pediatric years, with recent reports suggesting a rising incidence in the pediatric age group. This highlights the need for both pediatric and adult gastroenterologists to better understand issues related to the process of transition from pediatric to adult care. Research from other disciplines outside of IBD provide evidence that the transition period can be associated with poorer health outcomes and that a structured transition program may improve patient compliance and disease control. Recent data from the IBD literature support a need for transition clinics. The ideal model of a transition program has not been established. Controlled trials are not available to measure the impact of a structured transition program on clinically relevant endpoints such as disease control and hospital admissions. As local resources and availability of staffing and funding are highly variable, we have summarized some practical guidelines for the adult and pediatric gastroenterologist that can be used as an aid to help adolescents through the transition process even without the support of an established transition clinic.

Keywords

inflammatory bowel disease; pediatrics; transition process

Up to 25% of patients with inflammatory bowel disease (IBD) will first present in childhood or adolescence.¹ Recent reports suggest that the incidence in pediatrics is rising. In a retrospective study from the United States over an 11-year period, the annual incidence of IBD in the pediatric population doubled from 1.1/100,000 to 2.4/100,000.² In a U.S. population-based study the incidence of pediatric IBD was 7.05/100,000 with a 2-fold predominance in Crohn's disease compared to ulcerative colitis.³ A European population-based study showed a rise in the incidence of pediatric Crohn's disease over a 12-year period from 2.1/100,000 to 2.6/100,000.⁴ This growing cohort of patients will eventually move from pediatric to adult care, highlighting the need for both pediatric and adult gastroenterologists to better understand issues particular to the adolescent and the process of transition from pediatric to adult care. The purpose of this review is to highlight the need for

a structured transition process based on evidence from other disciplines and the large gap in the IBD literature in addressing this patient population's needs.

Transition is the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented healthcare systems.⁵ The transition of healthcare responsibilities from caregivers to patients encompasses more than the physical movement of a patient from the pediatric to the adult clinic or hospital.

Multiple guidelines have been proposed by national medical societies or experts in the field that provide consensus statements on transitioning adolescents and young adults with chronic illness,^{6,7} or specifically IBD.^{8,9} In 2002, a consensus statement on healthcare transition for young adults with special healthcare needs established a goal that by the year 2010 all physicians who provide care to young people with special healthcare needs 1) understand the rationale for transition from child-oriented to adult-oriented healthcare; 2) have the knowledge and skills to facilitate that process; and 3) know if, how, and when transfer of care is indicated.⁶ In the IBD community this goal has not been achieved. A nationwide survey of U.S. gastroenterologists reported 73% competence regarding medical aspects of adolescent care but only 46% competence with adolescent developmental and mental health issues.¹⁰

Transition to self-management involves gradual changes in knowledge, attitudes, and behavior.¹¹ During this process, adolescents assume responsibility for all aspects of their own healthcare, become informed consumers of the adult healthcare system, and redefine their role in the self-management of their condition.¹²

EVIDENCE FROM OTHER DISCIPLINES

Research regarding transitional care in IBD has been more sparse compared with other disciplines that also have a large proportion of pediatric patients with chronic disease, including cystic fibrosis,^{13–17} rheumatological diseases,^{18–26} diabetes mellitus (DM),^{27–35} organ transplant,^{36–42} and congenital heart disease.^{43–55} Reports demonstrate that both adolescent and young adult liver transplant recipients are deficient in self-management of their healthcare.⁵⁶ A qualitative study of solid organ transplant recipients found that the majority of subjects, despite indicating challenges in the transition process, preferred being treated as adults and being responsible for their own healthcare.⁵⁷ In pediatric liver transplant recipients, the transition period was associated with poorer medical adherence.⁵⁸ A further pilot study from the same authors found that a targeted education intervention for patients consisting of both education on their medical history and the process of transition improved medical adherence.⁵⁹ Analysis of data from 115 renal transplant patients revealed that the period of transition was not associated with renal allograft loss. However, as patients over the age of 18 years had a lower admission rate for management of rejection or for biopsy compared with the younger age groups, the authors hypothesize that these patients were not receiving proper medical attention.⁴¹

Patients with congenital heart disease who believed that they should transfer care to an adult center rather than stay at the pediatric center are more likely to attend appointments after transition.⁶⁰ In a large retrospective cohort study of 1507 young adults with DM followed until 20 years of age, physician continuity was a protective factor in DM-related hospitalization. Hospitalization related to diabetes rose from 7.6 to 9.5 cases in the 2 years after transition to adult care. Patients with no change in physician had a relative risk of 0.23 (95% confidence interval [CI] 0.05–0.79).³² Type 1 DM patients who transition under a structured process had improved clinic attendance and HbA1c levels compared with those referred to adult care by letter only.⁶¹ Similarly, a transition program involving a dedicated

coordinator and an after-hour phone support system was associated with reduced hospital admissions for diabetic ketoacidosis.⁶²

The majority of studies on transition tend to focus on descriptive data based on expert opinion or surveys of patient, family, and/or healthcare provider's perceptions or experiences of the transition process. In contrast, McDonagh et al⁶³ were able to construct a transition program based on a needs assessment of a group of patients with juvenile idiopathic arthritis. They measured quality of life at baseline and 6 and 12 months after the initiation of the transition program in 308 adolescents and found significant improvement reported by both patients and their families. Furthermore, the transition was designed to be developmentally age-appropriate, as the study recruited only 11-, 14-, and 17-year olds, each age reflecting a different stage of adolescent development.

In summary, the majority of the evidence from other disciplines supports the supposition that the transition period into adult care may be a vulnerable period and that having a structured transition program may have a positive effect on clinical and psychosocial outcomes.

INFLAMMATORY BOWEL DISEASE

To date, no large-scale study has compared outcomes of the transition process with or without a structured transition program for patients with IBD. A recent retrospective case-control study compared disease characteristics and compliance in 100 adolescents with adult controls matched for disease duration.⁶⁴ All adolescents were seen at a biweekly transition clinic of IBD patients ages 16–24. Patient management was shared between a pediatric and adult gastroenterologist as well as an IBD nurse. A greater percentage of adolescents required hospital admission (46% compared to 14% of adults, $P < 0.0001$), azathioprine (46% compared with 17% of adults, $P < 0.0001$), and infliximab (20% compared with 6% of adults, $P < 0.05$). Adolescents missed a median number of 20% of their appointments compared with 0% in adults ($P < 0.0001$). Overall, these results support the need for a transition clinic, as adolescent patients may have more severe disease compared with adult patients with the same duration of disease and have lower rates of compliance to clinic follow-up. Furthermore, given that adult gastroenterologists will ultimately take over the care of these patients, it suggests that they should get involved early on in the care of these patients.

Hait et al⁹ published a review on the suggested protocol for the transition process. Since this publication, a study from the same authors found that there continued to be gaps in patient knowledge, as a survey of adult gastroenterologists revealed that deficits in patient knowledge of medical history and medications are the two most important perceived problems during transitioning to adult care.¹⁰ A medication adherence questionnaire study of 64 adolescents found that the most frequently reported barriers to taking medications appropriately were lack of time (33%), feeling well (16%), and belief that the medication was ineffective (14%) or had side effects (14%).⁶⁵ Another study of 90 adolescents found that longer time since diagnosis, greater perceived disease severity, and lack of autonomous motivation to adhere predicted lower adherence to prescription medications.⁶⁶

While a small study of patients and families who had undergone transition predominantly through the use of a joint visit attended by both adult and pediatric gastroenterologists reported the experience as positive,⁶⁷ the literature remains relatively void of studies to answer the question of the impact of a structured transition program on patient outcomes.

Existing transition programs and clinics are highly variable, ranging from primarily educational didactic modules, joint visits with both pediatric and adult physicians,

alternating visits between the pediatric and adult sites, or having a dedicated nurse transition coordinator. The ability to structure a transition program depends on local factors such as patterns of referral, funding, reimbursement, nursing and allied healthcare support, and distance from tertiary care centers for patient travel. No data exist on the most successful way to transition adolescents and young adults to adult care, and thus no consensus has been developed to provide an “ideal model.”

DIRECTIONS FOR FUTURE RESEARCH

We hypothesize that young adults undergoing the transition process may face a variety of barriers, including 1) psychological distress,^{68,69} 2) lack of cognitive understanding, 3) parents who continue to take the majority of responsibility,⁷⁰ 4) lack of trust in the adult medical team, 5) lack of understanding of how the adult healthcare system works, 6) negative perception of adult healthcare,⁷¹ and 7) loss of insurance. These factors may play a role in making the transition process more difficult and may consequently impact disease activity and complications.

The evidence from other disciplines suggests that medical compliance is poor during the period of adolescence and transition. Recent studies of IBD adolescents show multiple barriers to medical compliance including perceived lack of time, duration of disease, and belief in the efficacy of medical therapy.^{65,66} It is essential to understand the needs of patients and their families during the transition process. Studies are needed to measure medical compliance and disease course pre- and posttransition. Controlled trials are necessary to determine the efficacy of a structured transition process with clinically relevant endpoints such as disease control, hospital admission and surgery, disease- and drug-related complications, and quality of life. With the rising incidence of childhood IBD this is an area that demands systematic investigation. As reimbursement may be an issue in the U.S., documenting that particular transition models are of benefit in improving outcomes and reducing hospitalizations and surgeries will be important to fund proper transition.

The ideal model for the transition process of patients with IBD has not been established and likely will depend on institutional and local resources. General guidelines have been proposed by both Canadian and U.S. pediatric societies for the transition to adult care for youth with special health-care needs that have now been adapted for IBD patients.^{6,7} Tables 1 and 2 provide summary guidelines for IBD programs to aid patients through the transition process.

1. Healthcare providers need to recognize that pediatric-and adult-oriented healthcare represent two different cultures. Pediatric IBD care is family-focused, with significant parental involvement within a multidisciplinary team, including a nutritionist, social worker, and psychologist/psychiatrist if needed. Adult healthcare is focused on individual healthcare often without the resources for a multidisciplinary team.
2. Asking patients and families about their expectations and fears of transition is important. In academic centers this may serve as a formal needs assessment to base future transition care programs. In community and individual practices this may be informal in the form of questions during follow-up visits, but may serve to acknowledge that healthcare providers recognize that the transition process can be a time of stress for patients and families.
3. Adolescent patients and their families should be educated on the differences between pediatric and adult healthcare.

4. Although it may not be feasible to identify the specific adult gastroenterologist that will be taking over care, we suggest providing a written healthcare transition plan (which can be updated regularly) by ages 16–23 that identifies the following:
 - i. who will take over care (individual physician or IBD center);
 - ii. the tasks that the adolescent will need to master before entering the adult healthcare system (Table 3);
 - iii. how the care will be financed, as patients and their families may be unprepared for possible changes in health insurance when patients are no longer considered dependent children.
5. The actual provision of transition services will be highly dependent on local funding and resources but may include: individual education by a physician, nurse clinician, psychologist, or social worker; educational groups; written materials including checklists for patients and parents; joint transition clinics; and Web-based tools.

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TABLE 1**Recommendations for Pediatric Gastroenterologists**

Awareness that transition is an ongoing process that may begin as early as the time of diagnosis of IBD
Ask patients and family members their expectations of the transition process
Patients should be given information about their disease and the treatment plan both verbally and in written form
Provide opportunity for patients, when developmentally appropriate, to be seen in clinic on their own for at least part of the visit
Create a written healthcare transition plan together with the patient and family that can be updated on an annual basis
Highlight differences between pediatric and adult care as situations arise. For example, educating UC patients that surveillance colonoscopies need to start after 10 years and that in the adult system this would be done with conscious sedation

TABLE 2**Recommendations for Adult Gastroenterologists**

Awareness that pediatric patients entering the adult healthcare system for the first time may not be fully prepared or aware of the differences between the two systems

Collaboration with the pediatric gastroenterologist and team prior to the actual “transfer” of care. Examples: participation in transition clinic, information sessions

Anticipate questions from patients about IBD, treatment plans and impact on body image, and sexual health

Educate the patient in understanding the adult health care system

For newly transferred patients the first few visits may require longer appointment times.

Anticipate that parents may want to continue to have a key role in their child’s care and that patients may not be able to provide the complete medical history without their parents input. Although the goal is for patients to take on responsibility for their own care the process may be gradual.

TABLE 3**Suggested Knowledge and Tasks that Adolescents Should Master by the Time They Attend an Adult Care Clinic**

Diagnosis (Crohn's disease, ulcerative colitis, indeterminate colitis)
Anatomic location of their disease
Extraintestinal manifestations
Year of diagnosis, and names of their IBD institutions/hospital/healthcare providers
Dates of hospitalizations, why they were hospitalized, events during hospitalizations
Dates of surgery and the procedure performed
Complications of their disease or therapy, e.g., fistulas, abscesses, opportunistic infections, pancreatitis, cytopenias
Names and doses of drugs they are currently on and have taken in the past
Insurance plan and contact information
Can make arrangements for blood tests and understands who to call for follow up on the results
Calls the appropriate healthcare provider in the event of a disease flare
Calls the appropriate healthcare provider to refill medications
Can schedule their own visits and remembers to attend
Understands which medications can potentially be harmful during pregnancy and the need to discuss with healthcare provider issues regarding contraception and planning for children

Exact timeline may begin as early as diagnosis and the timeframe for achievement of each item will be dependent on individual patients.