Transitional Care in Inflammatory Bowel Disease

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Abstract: Transitional care is an organized effort to provide pediatric patients with the tools and resources they need to assume personal responsibility for their medical care while facilitating their transfer from a pediatrician to an adult practitioner. Since inflammatory bowel disease (IBD) is usually chronic and up to 25% of IBD patients are diagnosed before the age of 18 years, transitional care is an important consideration for adolescent and young adult patients. The importance of transitional care for chronic diseases that begin in childhood has been recognized in a number of published recommendations. However, most of these recommendations arise from intuitive reasoning, as physicians lack information regarding the need for transitional care, optimal delivery protocols, and the efficacy of transition programs. Even fewer studies have been published regarding transitional care in IBD. Current guidelines stress the importance of providing patients with educational resources to help them develop the skills they need to manage their care as independent adults, introducing the concept of transfer to adult care in advance of the actual transfer, and developing routes of communication to facilitate the transfer from pediatric to adult care providers. Future studies should aim to elucidate which programs are effective and how they should be implemented.

Keywords
Adolescent healthcare, inflammatory bowel disease, pediatrics, transition to adult medicine

Transitional care is an important consideration for adolescent and young adult patients with inflammatory bowel disease (IBD), as up to 25% of IBD patients are diagnosed before the age of 18 years and the disease is usually chronic.[1,2] Transitioning care for IBD patients as they progress from adolescence to adulthood may appear straightforward, but the process is actually complex.

Two conceptual elements form the basis for this healthcare transition. One is the transition of responsibility for care from the guardian to the patient. The second is the transfer of care from the pediatric doctor to an adult gastroenterologist. The transfer from pediatric to adult medicine is usually easy to identify, as it involves a physical move, whereas the patient's assumption of responsibility for care is a gradual change. These 2 processes are entwined, and the success of one requires the success of the other.

The transfer of a patient from a pediatrician to an adult practitioner is one of the few times a physician willingly relinquishes care of a long-standing patient who is still ill. As such, this transition is fraught with emotional overlays for both the physician and the patient, including grief of parting, fear of the unknown, and possibly a sense of abandonment.[3] Often, this move precipitates the second part of the transfer process: the shift in primary responsibility for management of care from the parent to the patient. For parents of patients with diseases that are difficult to control, who have often painstakingly maintained their child's health by intensive consultation with healthcare team members and aggressive pursuit of maximal efficacy of care, the transition process involves facing the fear that the patient's health may be jeopardized once neither they nor the healthcare professionals they have trusted control the course of care. Added to this burden are financial issues that impact the patient's access to care, including age-related termination of health insurance and loss of social support services.[3]

Transitional care programs are organized efforts to facilitate both the shift of responsibility from caregiver to patient and the move from one physician to another. This process, which aims to encourage patients' and families' confidence in the new healthcare providers, involves educating patients and their families and using structured means to enhance communication between the pediatrician and the adult physician.

In 2002, both the American Academy of Pediatrics (AAP) and the North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition (NASPGHAN) published position statements regarding transition of care. The stated goal of the AAP position statement was to ensure that, by 2010, "all physicians who provide primary or subspecialty care to young people with special healthcare needs: (1) understand the rationale for transition; (2) have the knowledge and skills to facilitate that process; and (3) know if, how, and when transfer of care is indicated."[4] The NASPGHAN statement specifically dealt with pediatric IBD and recommended that the pediatric gastroenterologist begin the process of transition by performing the following 4 steps: "(1) seeing adolescent patients without their parents … (2) discussing with the patient and family the benefits of transition to an internal medicine gastroenterology practice, (3) developing a relationship with an adult gastroenterologist who is knowledgeable in caring for young adults with a history of childhood-onset IBD, and (4) providing all of the necessary medical records and summaries so that the family will realize that all providers are working together to deliver excellent care."[5]

Transitional care for young adults with IBD has improved as the needs of this group have been recognized, but many challenges remain. Some basic facts are required in order to design effective transition programs, including data regarding the actual needs of the patient, information about the care to which patients are being transitioned, and understanding of which programs are effective for transition. Randomized trials with concrete outcomes are difficult to perform in this area due to the limited number of patients undergoing transition and the subjective nature of the interventions, making it difficult to collect the quality data expected with evidence-based medicine. Thus, an important challenge is to formulate appropriate questions and establish protocols that will collect the data needed to effectively structure a useful transitional medicine paradigm.

Data on Transitional Care in Other Fields

The literature regarding transitional care for patients with other medical conditions includes studies of patients with congenital heart disease, diabetes, hemoglobinopathies, psychiatric disorders, solid organ transplantation, and cystic fibrosis (CF).[6-11] Most of these reports are descriptive, with the results based on patient satisfaction rather than objective clinical outcomes.[12] Recommendations are based on best practices or clinical experience.

Recent data indicate that many patients are being lost in the system during the transfer process. In a cohort of Canadian patients with complex congenital heart defects, data were collected prior to the initiation of a formal transition program when transfer to adult care at the age of 18 years became required due to healthcare system regulations. Only 47% of patients were considered to be successfully transitioned, with 27% having had no follow-up appointments since the age of 18 years and only 50% of patients having had a documented discussion of adult care while still under pediatric care.[13] Similarly, Hazel and colleagues reported that 52% of patients with juvenile idiopathic arthritis did not transition successfully from a Quebec pediatric program, despite the presence of a structured transition program.[14] Another study found that prior to the institution of a transition program in Manitoba, 40% of patients with type 1 diabetes were lost to follow-up after transfer.[10] Although the diseases examined in these studies are diverse, the numbers of patients in the studies are small, and the study methods vary dramatically, these Canadian studies show that sizeable percentages of patients with chronic, severe diseases were being lost to follow-up during the transfer process.

Because of the way care for CF is organized in the United States, this disease can provide information about the evolution of the transition process. As life expectancy for CF increased and care for the disease changed, the need for transition became apparent. The Cystic Fibrosis Foundation (CFF) now requires that CFF-designated centers create an adult program when the center treats more than 40 patients over the age of 18 years. Since 2000, the goal of the CFF is to transfer 90% of patients over the age of 21 years to adult care. Despite this goal, a 2010 review of CF transitional care by Tuchman and colleagues reported that only 18% of centers had programs for the development of self-management tools and only 10% of centers had written self-management goals to assess readiness for transition.[7] The role that the CFF has played in guiding the development of transition programs may serve as a model for similar patient advocacy organizations.

One factor that improves the efficacy of transition programs is the presence of a local transition program director. The Maestro program for adolescents with type 1 diabetes in Manitoba includes various Internet, print, and social programs, as well as a navigator who biannually contacts patients. While 40% of the patients who were not enrolled in the program dropped out of adult care, the drop-out rate among patients contacted by the navigator was only 11%. In this study, some clinical outcomes were monitored, but no differences were noted.[10]

In a study of British rheumatology clinics, McDonagh and colleagues described a transition program for adolescents that incorporated a local program director, individualized age-specific templates, and a variety of information resources. Participants identified the access to educational resources as important, but the coordinator was reported to be the most valuable component of the program.[6] By comparing patients to their baseline prior to enrolling in the program and to historical controls, the study authors found that the program was associated with improvement in health-related quality of life. Although these improvements could not be separated from the natural progression of the psychosocial aspects of the disease, this study shows the importance of access to information and the presence of dedicated personnel to help patients navigate the transition process.[15]

In the realm of solid organ transplantation, where lapses of care due to transition may have dire effects, the data have not been reassuring. In one study, teenagers who had undergone liver transplantation were evaluated by drug levels, clinic visits, and a survey designed to determine if they were ready for transition; this study found that 30% were noncompliant with medication administration based on drug levels, 30% were noncompliant with clinic visits, and the risk of noncompliance increased with age. Surprisingly, higher scores on the self-management survey correlated with greater drug noncompliance; the authors surmised that compliance dropped as the teenagers became older and took control of their medications.[9] This finding lends serious concern to the timeline envisioned for healthcare transition and highlights an important area of study.

Data on Transition in Inflammatory Bowel Disease

Approximately 15–25% of IBD patients are diagnosed before the age of 18 years.[1,2] Thus, a number of IBD patients will require transition to adult care, and data suggest that patients who are diagnosed with IBD at a younger age have more aggressive disease, making effective continuity during transition even more important.[16] Published data regarding transitional care for IBD are limited to several survey studies.

Dabadie and colleagues surveyed 48 patients in their late teens who were being treated in a French university IBD clinic to evaluate the effectiveness of a joint outpatient office visit including both the transferring pediatric physician and the adult gastroenterologist who was assuming the patient's care. The authors compared patients who underwent the joint visit with those who did not; these groups were not randomized, however. Rather, the groups were determined by circumstances that prevented the joint visit, such as hospitalization or lack of ability to coordinate the visit. The group that underwent the joint visit had significantly more active disease, and these patients were more frequently on immunomodulators and biologic therapy. Despite the marked differences between the groups (or possibly because of these differences) as well as the study's small sample size, the authors did not detect a significant difference in attitudes or perceptions of transfer between patients who experienced the joint visit and those who did not. Of the entire group, more patients (85%) than parents (74%) felt ready for the transfer.[17]

In another study, a survey asking adult gastroenterologists about their experience with transitional patients within the United States, key areas of weakness were identified. Of those physicians surveyed, 69% noted a lack of understanding on the part of the transitioning patient about their medications, 55% reported that their patients lacked adequate understanding of their medical history, and 51% noted inadequate receipt of medical records from the transferring physician. In addition, 51% of respondents reported that patients lacked knowledge about the impact of smoking and drinking on their disease. On the part of the adult practitioners, only 46% reported that they were competent in areas of young adult and adolescent healthcare, including developmental and mental health issues.[18]

Although there are no published data about the status of transition programs in the United States, transition programs are provided by 39–77% of pediatric IBD centers in the United Kingdom, where there is social support for such programs.[19,20] No published studies have reported the benefit of transition programs in IBD, but there is great interest in the results of an ongoing randomized trial being conducted by Schwartz. The treatment group will undergo 2 joint visits with the adult and pediatric physicians, and the primary outcome being measured is the number of hospitalizations for IBD flares at 1 year.[21] As focus on this aspect of IBD care grows, other studies will hopefully provide data regarding both the benefits of and the most effective measures for this healthcare transition.

Social Challenges Influencing Care for Young Adults in Transition

Financial Issues

In the United States, young adults are one of the groups at high risk for lack of insurance, with 28.9% of persons aged 18–24 years lacking healthcare insurance.[22] Data from the National Health Interview Survey 1999–2002 reported that 26% of young adults aged 19–29 years who had a disabling, chronic health condition were uninsured, and 35% reported a health need that was unmet due to cost. Forty-five percent of the uninsured had no regular source of care.[23] Although the Patient Protection and Affordable Care Act of 2010 aims to improve access to insurance for young adults, the actual effect of this legislation will not become clear for some time.[24]

Reproductive Health

Fertility and reproductive issues are of key importance at or around the age when individuals are commonly transitioned to adult care, and pregnancy is often an event that precipitates the transfer of care to an adult provider. The highest birth rate in the United States is for women in their 20s.[25] Pregnancy carries a higher risk in IBD patients than healthy women and thus requires careful medical attention.[26]

Studies in other fields report a need for more information about reproductive health. Adolescents in transplant clinics report a need for more information on fertility, health, and high-risk behaviors, but these individuals often hope to obtain this information without their parents' knowledge.[27] Eighty-seven percent of CF patients in an Australian clinic reported that they had received no information on sexual health.[28] Studies of sexual activity in chronically ill adolescents reveal that they engage in high-risk behaviors as frequently as teenagers without illness. There was no difference in pregnancy rates among chronically ill and healthy teenagers, and some data reveal higher rates of sexually transmitted diseases in ill teenagers.[29]

Substance Use and Abuse

Most studies find that drug abuse and tobacco use occur at lower rates among chronically ill teenagers than the general population, but these issues are still present and may impact care.[29] Substance abuse was associated with a lower rate of successful transfer in a cohort of Canadian teenagers with complex congenital heart defects.[13] In regard to behaviors that may influence disease activity, a study of patients with Crohn's disease (CD) in a Chicago IBD center revealed a smoking rate of 19–24% among patients 18–24 years of age.[30] Screening for substance use is necessary in these patients, and resources should be available to reduce the impact of these behaviors when they are identified.

The Effect of Disease on Development

Chronic disease is known to affect important areas of adolescent development, including independence, body image, peer group, and identity.[31] Just as active disease during childhood may be permanently detrimental to the patient's overall height, active disease may also prevent the development of skills and pursuit of activities that allow the individual to become a functional adult in terms of relationships, education, and vocation. Patients with active disease are known to have lower rates of participation in the workforce, but the extent to which this is due to the impact of childhood disease as opposed to disease-related disability is unclear.[32] Although behavior issues, including truancy, are noted in adolescents with IBD, the effect of childhood illness on adult success is also unclear.[33] Healthcare practitioners assuming care of these patients should be aware that chronically ill individuals may be delayed in meeting developmental milestones during late adolescence, and these practitioners should also be aware of resources that may assist in these needs, such as vocational training, social work, and other forms of counseling.

In conclusion, practitioners who care for teenagers and young adults with IBD should keep in mind challenges that may limit access to care and be well versed in screening for and counseling patients about issues related to reproductive health, substance abuse, and psychosocial development.

Organizing a Transition Program

Transitional care occurs in several phases (Figure 1). In the first phase, the caregivers are solely pediatricians. The second phase ideally involves overlap between the influence of both the pediatric and adult spheres. Finally, in the third phase, adult providers assume sole responsibility for care.

During the pediatric phase, resources and education should be provided to allow the patient to successfully assume responsibility for their care. One example of an age-based template is reported by Hait and colleagues; according to this timeline, patients begin to meet expectations, such as naming their medical condition and

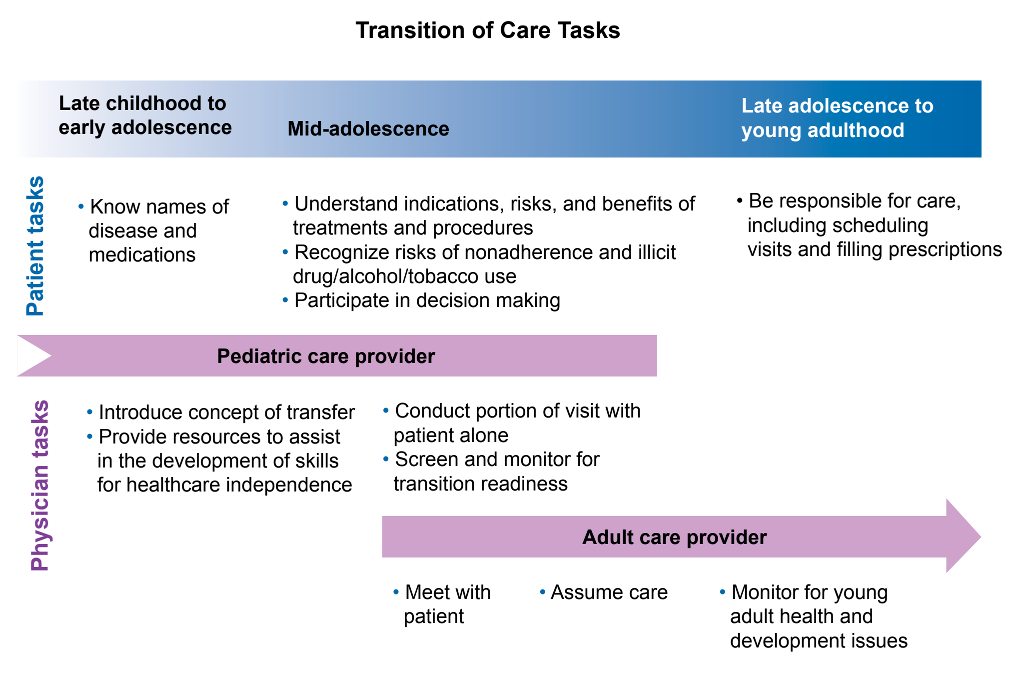

Figure 1. Representation of basic healthcare transition tasks for providers and patients in a flexible timeline. During care, physicians should provide ongoing, age-appropriate education about medications, disease course, reproductive health, substance abuse, and future treatment plans. Assessment of patient and family goals for care and obstacles to transition and transfer should also be performed. Actual transfer to an adult care provider occurs either during late adolescence or early adulthood, depending on maturity, readiness for transfer, and a variety of social and economic factors.

medications, beginning at 11 years of age.[34] Transition readiness surveys are also useful, such as the Transition Readiness Assessment Questionnaire, a validated survey that assesses patients' skills for self-management of chronic conditions, their self-advocacy, and their healthcare utilization.[35] These tools may be used to guide the transition process as well as assess readiness and track progress toward meeting developmental goals. It is recommended that the topic of the eventual transfer to adult care be introduced during this time.[5]

While not always logistically possible, a period of overlapping care seems advisable. This period may be approached in a variety of ways. Some programs include joint visits, with the pediatric and adult physicians present in the same clinic. A visit or interview with the adult physician prior to the actual transfer is also a means of overlapping care.

In situations where there is no direct overlap or collaboration between the adult and pediatric physicians, the transfer of information is even more critical. In the survey of adult gastroenterologists assuming care of pediatric IBD patients, lack of information was identified as a critical problem.[18] The role of a transition program director might also be of greater importance in situations where a formal overlap of care is not possible, as this individual can maintain contact with the transitioning patient and prompt the patient to initiate further contact or care if he or she becomes lost to follow-up while transitioning to the new, less forgiving, adult system.

In the final step of the transition process, the transfer has occurred and the patient is fully under the care of the adult physician, but the patient must still be considered a young adult. Because the risks and final developmental goals of the late teenager/young adult period remain an issue, the adult physician should screen for reproductive health knowledge and evidence of substance abuse, as well as remain aware that the chronically ill patient may have yet to meet his or her final developmental goals.

Learning from Transitional Care

As formal transition programs are developed, tracking this cohort of patients should provide more knowledge about the natural history of IBD, along with insights that could enable care providers to better treat chronically ill children. Since diagnosis at a young age is an indicator of more aggressive CD, information obtained through a successful transition program may shed light on the mechanisms behind the more serious prognosis seen in these individuals.[16]

Data should also be collected to assist in determining how care provided during the formative years may be improved to facilitate better psychosocial functioning in adults who have suffered from chronic disease since childhood; in particular, these data should examine the sequelae of disease, compliance, and dependence on narcotics. In a study of the effects of psoriasis, which is a classic example of a condition that can be disfiguring and debilitating when left uncontrolled, Kimball and colleagues developed the concept of "cumulative life course impairment." This concept aims to evaluate the cumulative effect of both the physical and psychological effects of the disease, as well as its economic and social sequelae, on patients' ability to live their lives to their full potential.[36] Given the impact of IBD on physical and social function and body image, the disease's impact on cumulative life course impairment might be similar to that seen with psoriasis. These social epidemiologic tools should be investigated for use in evaluating the overall impact of IBD on the patient, as well as their ability to track outcomes of transition programs.

Finally, there is hope that the transition process might be empowering for patients and may reduce rebellion in the form of noncompliance. Some data suggest that autonomy may improve compliance in chronically ill youth.[37,38] Thus, the tools used to prepare for transition might improve the course of care in adolescence, and studies to evaluate the benefit of transitional care should focus on this area as well.

Conclusion

The significant lack of understanding surrounding these topics provides an opportunity and a challenge as physicians strive for excellence in creating a transition process for pediatric IBD patients. This process is important both at academic centers and private offices, whether they are dedicated IBD centers or general gastroenterology practices. Developing better communication is a key part of this process—both communication with patients ready to transition and communication between the pediatrician and the adult physician. Table 1 lists specific steps that pediatricians and adult gastroenterologists can take to improve this transfer.

Table 1. Improving Transfer of Care in Inflammatory Bowel Disease (IBD) Patients

Recommendations for pediatric gastroenterologists who treat IBD:

- Continue to improve efforts to educate patients so that they can begin to assume responsibility for their care.
- Begin to plan for and discuss transition early in the course of care.
  - The American Academy of Pediatrics recommends that all children with chronic health issues have a written transition-of-care plan by the age of 14 years.[4]
  - Various timelines can be based on best-practice recommendations. Hait and colleagues have published a detailed review that includes a recommended checklist of transition tasks based on age.[34]
- Identify adult practitioners with competence in the treatment of IBD with whom effective communication may allow continuity of care.

Recommendations for adult gastroenterologists who participate in the care of young adults:

- Pursue education to become competent in key areas of adolescent and young adult care, including fertility and sexual health, drug abuse, communications, healthcare finance, and age-specific developmental goals.
- Develop mechanisms within the office to ensure that the proper information is being received from referring pediatricians.
- Develop relationships with referring providers to enhance communication. Feedback regarding outcomes may be essential in improving the process for subsequent patients.

Proposed areas of study for adult and pediatric practitioners interested in conducting research and developing structures of formal transition programs:

- Identify core measures to assess transition readiness. While standard tools such as the Transition Readiness Assessment Questionnaire exist, the development of an IBD-specific survey might be useful in these efforts; such a tool might include IBD-specific elements such as knowledge of nutrition and immunosuppression.
- Collect data to determine which transition clinic processes are optimal and cost-effective.
- Develop data to determine the optimal age or stage of development for transfer.
- Develop tools to monitor meaningful outcomes related to both medical outcomes and health-related quality of life.

Blum and colleagues described transitional care as "a purposeful, planned movement of adolescents and young adults with chronic … conditions from child-centered to adult-oriented healthcare systems" in a manner that addresses their medical, psychosocial, educational, and vocational needs.[39] A transition program may either be a physical clinic with a dedicated, multidisciplinary group of care providers or a conceptual element of the care provided in a more traditional clinic setting. The cost, staff, and space requirements of a physical transition clinic might limit such clinics to institutions that have the necessary resources, but not all patients transition to large groups such as academic centers. In fact, a survey by Hait and colleagues found that 69% of adult gastroenterologists identified as practitioners with an interest in IBD were in private practice.[18] As such, transitional care must be part of the education and practice of all pediatric gastroenterologists who care for IBD patients and all adult gastroenterologists who assume their care. The focus on transitional care is now gaining clinical and research interest, but data and resources remain lacking. Nonetheless, the overarching goal is quite simple: to provide the best care possible that will allow these patients to become as functional, healthy, and well adults as their disease allows. The mainstay of all of these programs is communication; programs should educate patients and families beginning early in the process and facilitate communication among transitioning providers to improve continuity and confidence in the process.

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