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Evaluation of Outcomes in Adolescent Inflammatory Bowel Disease Patients Following Transfer From Pediatric to Adult Health Care Services: Case for Transition

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ABSTRACT

Purpose: We aimed to evaluate the impact of a transition service on clinical and developmental outcomes in adolescent Inflammatory Bowel Disease (IBD) patients on transfer to adult health care services.
Methods: We reviewed the records of IBD patients diagnosed in pediatric care following their transfer/attendance to the adult IBD service. The data on patients who attended the transition service were compared with those who did not pass through the transition service.
Results: Seventy-two patients were included in the study 41M and 31F. Forty-four patients went through the transition system (Group A), and 28 had no formalized transition arrangement before transfer (Group B). A significantly higher number of Group B patients needed surgery within 2 years of transfer when compared with patients in Group A (46% vs. 25%, $p = .01$). Sixty-one percent of patients in Group B needed at least one admission within 2 years of transfer when compared with 29% of Group A patients ($p = .002$). Nonattendance at clinics was higher in Group B patients with 78% having at least one nonattendance, whereas 29% of Group A failed to attend at least one appointment ($p = .001$). In addition, drug compliance rates were higher in the transition group when compared with Group B (89% and 46%, respectively; $p = .002$). A higher proportion of transitioned patients achieved their estimated maximum growth potential when completing adolescence. There was a trend toward higher dependence on opiates and smoking in Group B patients.
Conclusions: In adolescent IBD patients, transition care is associated with better disease specific and developmental outcomes. Prospective studies of different models of transition care in IBD are needed.

IMPLICATIONS AND CONTRIBUTION

Many expert reviews and consensus statements have recommended transition care for patients with IBD. However, the impact of transition has not been studied adequately. This study evaluates the clinical and developmental outcomes of a structured transition service for IBD patients. Findings show that transition care has a positive impact on disease outcomes, paving the way to develop new models for transition care in IBD.

Inflammatory bowel diseases (IBD) (ulcerative colitis [UC] and Crohn's disease) are chronic relapsing and remitting disorders having a significant negative impact on quality of life in those affected. Inflammatory disease presents in childhood or adolescence in about 25% of those affected, and there are data to suggest that the incidence in pediatric years is increasing [1]. Pediatric patients appear to have more extensive disease when compared with adults and often need surgery and hospitalization [2,3]. Self-management is an important component of these conditions and monitoring of disease, adherence to treatment, and life style factors such as diet, and smoking plays a crucial role

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Conflicts of Interest: The authors have no conflicts of interest to declare.

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in the disease course [2]. The patients diagnosed with IBD in childhood will eventually need to move from the family-centered multidisciplinary setup of the pediatric centers to adult gastroenterology teams, where greater patient independence and self-management is expected. This movement often occurs at a crucial time of significant physical and psychological change, and the adolescent also has to cope with the effects of a chronic disease. Hence, there is increasing interest in the concept of transition before transfer for these patients. Although "transfer" from pediatric health care system to adult care system is essentially an event, "transition" is a purposeful and planned process addressing medical, psychological, developmental, and vocational needs of adolescents and young adults when they move a child centered to an adult-oriented health care system.

Data from other chronic disease populations such as diabetes and rheumatoid arthritis indicate that the transition period can be associated with adverse physical and psychological outcomes, and there is some evidence that a coordinated and age appropriate transition program may improve disease outcomes [4,5]. The available literature on transition in IBD is limited to provider surveys [6,7] and expert opinions, [8–10] which are largely based on data from other disciplines. There are few models of transition care in IBD such as use of dedicated adolescent and young adult clinic and using single or multiple joint clinics with pediatric and adult health care providers [8]. However, there are no studies measuring the impact of a transition program on definable outcomes in IBD, such as surgery and admission rates. Although some aspects such as developmental outcomes, quality of life, and self care goals may be similar for all chronic diseases, understanding the effect on disease specific outcomes is important in evaluating transition programs in IBD. Moreover, such data would be useful in determining funding and reimbursement of services.

We aimed to study the disease specific and developmental outcome measures in a cohort of IBD patients, diagnosed in pediatric care, following their transfer to adult gastroenterology services with or without attendance to a transition service.

Methods

Participants

This study was a retrospective review of records of patients whose IBD was diagnosed in pediatric care in our institution from January 2006 to January 2014. In this period, 128 patients were diagnosed with IBD in the institution before the age of 16 years based on pathology records. Nine patients (seven before setting up transition clinic) were lost to follow up until the study period or were being followed up in other institutions (two patients) before their transfer to other adult IBD services, and these patients were excluded from the study. Forty-six patients who were attending transition clinics at the time of analysis and not yet transferred to adult care were also excluded. The transition clinic in our institution was set up in January 2009 following patient and parent feedback. It was held alternatingly in pediatric and adult outpatient environments and involved joint consultations with adult and pediatric gastroenterologist along with support from IBD nurse and dietitian with a clinical psychologist as required. Patients were minimum 15 years old and attended the clinic along with their parents initially but were encouraged to attend consultations themselves before transfer. Patients and parents received detailed disease specific education and information specific to individual patients. An individualized transition plan was made for each patient. At each visits, patients had a global assessment of suitability to transfer in the opinion of both adult and pediatric teams based on measures such as disease control, growth, and development, independence of medications, disease education, and schooling, but we did not use any validated tools to assess readiness to transfer. Before the setting up of the transition clinic, patients were referred to the adult gastroenterologists by patients' general practitioner (GP) after their discharge from pediatric care or pediatric gastroenterologist with a referral letter after the patient has reached the age of 16.

The start of transition was defined as the first registration to the transition clinic. Transfer was the date of first registration to exclusive adult gastroenterology/IBD clinic. Patients were divided into the following 2 groups: Group A—those who attended transition clinic and then transferred to adult care and Group B—patients transferred to adult care without attendance in transition clinic. All the Group B patients were transferred before the transition clinic was set up in 2009. Hence, Group B patients had longer disease duration and follow up in adult care at the time of analysis, and therefore, we decided to look at outcomes within 2 years of transfer/registration to adult service in both groups.

Measures

We collected data on demographics, age at diagnosis, age at registration with adult services, and mode of presentation (emergency, referral from GP and/or pediatric gastroenterologist or transfer following attendance in transition clinic) to adult services. We defined disease activity at transfer into four groups: (1) disease in remission with or without treatment; (2) active disease on treatment; (3) active disease not on treatment; and (4) active disease needing admission at first presentation to adult service. In both groups, we collected data on Montreal class at presentation, recorded adherence with clinic attendance, any surgery or hospital admissions within 2 years of transfer, and estimated radiation exposure in millisieverts from radiology records. We also looked at patient reported adherence with medication as recorded in their notes during clinic visits. Employment and/or academic status at the time of last visit to the adult clinic was recorded. We also reviewed the growth charts to ascertain whether the patient has achieved their growth potential defined as reaching within two standard deviations of mid-parental height and having a normal body mass index at age 18.

Data analysis

The data were analyzed using SPSS (IBM Corp., Armonk, NY). Demographics are presented as median and range. The outcome variables between the two groups were compared using Fisher's Exact test and the Mann–Whitney test as appropriate. p Value $<.05$ was considered statistically significant.

The study was primarily designed to evaluate a clinical service of transition care in IBD and received service evaluation approval by our institutional review committee and hence did not require formal ethical approval according the U.K. research and audit guidelines [11].