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Observational Study

Transition care in inflammatory bowel disease: A needs assessment survey of Quebec gastroenterologists and allied nurses

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Abstract

AIM

To determine the tools needed and problems encountered during the transition of inflammatory bowel disease (IBD) patients from pediatric to adult gastroenterologists (GIs) in Québec, Canada.

METHODS

We conducted a needs assessment survey of Quebec health care professionals (HCPs). The survey was handed out to 136 Québec HCPs at a local conference in 2013. Additionally, it was emailed to any other HCPs in Quebec involved in caring for IBD patients. The completed surveys were compiled to derive descriptive data. Further specific subgroup analysis was then conducted.

RESULTS

Among the conference attendees and individuals emailed

77 (28.2%) completed the questionnaire. Respondents included adult GIs (61.3%), pediatric GIs (20.8%) and IBD nurses (18.3%). The majority of respondents believed that a standardized structure is important for a successful transition. Adult and pediatric GIs equally felt that patients were inadequately prepared for the transition ($P = 0.6$). There were significant differences between adult and pediatric GIs when it came to resource availability (55.6% *vs* 90.9%, $P = 0.002$) and perceived need of a formal transition clinic (21.7% *vs* 68.8%, $P = 0.0006$). Both transition program and medical summaries were identified as the most valuable tools to improve transition.

CONCLUSION

As described in previous studies, our survey reinforces the importance of a transition program, education for young adult IBD patients and the need to improve communication between adult and pediatric GIs.

Key words: Inflammatory bowel disease; Transition; Paediatric; Canada; Tools; Health care professionals

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Core tip: Transition care and transfer of care from pediatric to adult realms is a major challenge with a paucity of published work in the inflammatory bowel disease (IBD) domain. Transition care varies across different health care systems but from other pediatric entities improved objective outcomes have been demonstrated with more effective transfer of care. This is the first published survey on health care professionals (HCPs) opinion on transition care in IBD in Canada. Barriers related to the patients from the HCPs were identified as were tools that if implemented have potential to improve the effectiveness of transition care. Differences between pediatric and adult gastroenterologists were also identified.

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INTRODUCTION

Inflammatory bowel diseases (IBD), which encompasses both ulcerative colitis and Crohn's disease are common pediatric idiopathic chronic diseases^[1,2]. Estimates have shown that approximately 20%-30% of cases of IBD are diagnosed before the age of 18^[2,3]. Data also indicate that the incidence and prevalence of IBD have both been increasing over time^[4,5] and Canada has been shown to have one of the highest rates worldwide^[5]. Hence there exists an inevitable need to manage this growing population and the chronic

nature of the disease mandates to establish effective means of coordinating efficient transition care from the pediatric to the adult realm.

There are a number of significant differences between pediatric and adult systems most notably a paradigm shift from a dependent, multidisciplinary and family centered setting in pediatrics to an autonomous and self-reliant framework in the adult system^[6-9]. Transition care as defined by the Society for Adolescent Medicine is the "purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health-care systems"^[10]. Although lacking convincing objective evidence, there is expert consensus that a coordinated transition between the pediatric and adult realm is essential in the management of IBD^[7,11-13]. Transition care provides adolescents the opportunity to acquire the set of skills required to succeed once they are integrated into the adult system. Numerous challenges, both patient and health care system related factors, currently exist making it difficult to consistently achieve successful transition care^[9]. Particularly in Canada we face the challenge where patients are expected to become part of the adult system at the age of 18, as they are no longer eligible to be seen in a pediatric setting.

There remains a paucity of published literature on IBD transition. A number of publications have focused on surveying transitioning pediatric patients focusing on their knowledge of their medication, ability to identify associated adverse events, quantifying medication adherence and evaluating their capacity to demonstrate independence^[14-16]. Health care providers perception has also been a focus of research to aid in identifying domains to target for transition care amelioration^[11-13]. Certain tools guided at improving transition have also been studied such as The MyHealth Passport from the University of Toronto and TRANSITION tool out North Carolina^[17,18]. To date, no concrete data has been published demonstrating any improvement in a pre-determined objective outcome variable with a dedicated standardized transitional care network.

In Quebec, the Transition to Adult care in patients with Crohn's and Colitis (TRACC) program has been established in collaboration between adult and pediatric gastroenterologists with the aim of facilitating and improving transition care in patients with IBD while trying to overcome some of the common obstacles encountered. Currently, in Quebec the age to initiate transition is variable with no standardized age of initiation. On the other hand, the age of transfer of care is fixed at 18 across the province. Previous studies have looked at adult and pediatric gastroenterologists (GIs) perspective of transition care, however no data exists on the perspective of adult and pediatric GIs in the Canadian health care system, more specifically from Quebec. Moreover all of the studies conducted have focused on the perception of transition and barriers to successful transition with none looking at specific tools that may be

of use to yield more successful transition care^[11-13]. To our knowledge none of the published conducted studies on surveys focused specifically on needs assessment.

The primary objective of our study was to determine the necessary tools and obstacles encountered during the transition of IBD patients from pediatric to adult care from the perspective of health care professionals (HCPs) in Quebec, Canada. The information obtained via the survey will then serve as a basis for establishing methods to achieve more effective transition care. Secondary objectives included comparing pediatric and adult gastroenterologists and identifying any significant differences between the two groups.

MATERIALS AND METHODS

Study design

We performed a cross sectional needs assessment study that was conducted in the province of Quebec between November 2013 and August 2014. We intended to include all HCPs that care for pediatric and adult IBD patients. A total of 136 paper copies of the questionnaires were handed to all HCPs attending the annual association des gastroenterologues du Quebec (AGEQ) meeting in November 2013. In addition, through the contact list provided by the AGEQ, an email was sent to all members of the association (total of 206 individuals) of which included only board certified adult and pediatric gastroenterologists. Within this email it was specified to all members to not fill out and return the survey if they had attended the conference in November (a total of 96/206 members were at the conference). Members were all required to print out the survey and either mail it to our office or bring it by in person.

Survey/questionnaire

The questionnaire was intended to elicit the opinion of health care professionals on various aspects pertaining to transition care in pediatric patients with IBD. The questionnaire was developed by the TRACC committee, which is made up of adult and pediatric IBD specialists and expert IBD nurses. The questionnaire has not been previously validated but was developed to have a better understanding of the reality of transition care in Quebec. There is no validated questionnaire in existence geared at assessing health care provider perception of transition care in IBD. Certain components that were included in the two surveys previously published prior to our survey's inception^[8-9] were also incorporated into our questionnaire. Basic demographic data was collected. With respect to age of transition care initiation and completion respondents were able to choose between different age choices (Initiation: 12, 13, 15, 16, 18; Completion: 16, 17, 19, 20). In addition respondents were asked to rank the degree of importance of different statements describing certain factors related to transition on a Linkert scale from 1 to 5, in which 1 represents "not important" and 5

represents "very important and essential". Additional questions were to investigate the current efficacy of transition through transmission of summary letters from the referring pediatricians what components should be included within the transfer note. The latter section of the questionnaire inquired about what tools, if implemented, would be perceived as beneficial in improving the quality of transition in Quebec.

Statistical analysis

All the completed surveys were compiled and entered into an Excel document, which was then used to derive summary descriptive data. Included in the summary descriptive data was subgroup breakdown. The response rate of every question varies as not all respondents answered all the questions. A respondent was included in the analysis if > 50% of the questions were answered (only 1 survey was excluded ultimately). Differences between subgroups on specific questions was explored using χ^2 analysis with the threshold for significance set at a $P < 0.05$. A two-tailed T -test analysis with the assumption of unequal variance was used when comparing means of two different groups for the two age-related questions.

RESULTS

Demographics of respondents

A total of 273 surveys were handed and 77 were filled out yielding a response rate of 28.2% (77/273). Respondents included adult gastroenterologists (GIs) ($n = 47/77$, 61%), pediatric GIs ($n = 16/77$, 20.8%), IBD nurses ($n = 14/77$, 18.3%). 41.6% of individuals ($n = 32/77$) worked in non-academic hospital setting while 57.1% ($n = 44/77$) work in academic centers while only 1 individual worked uniquely in an outpatient clinical setting. Looking at response rates of demographic subgroup based on total number of professionals in Québec 25.5% ($n = 47/184$) of adult GIs and 72.7% ($n = 16/22$) of pediatric GIs responded. With respect to experience 52.6% ($n = 40/77$) had greater than 10 years of experience, 23.7% ($n = 18/77$) had 5-10 years of experience and 23.7% had less than 5 years of experience ($n = 18/77$) (Table 1).

Importance and age of transition

Almost all respondents felt that a standardized structure for transitioning patients with IBD was important (97.4%, $n = 75/77$). Out of these 62.3% ($n = 48/77$) felt this was very important while 35.1% ($n = 27/77$) felt it was moderately important yet important enough to merit a standardized structure (Table S1). There was no significant difference on subgroup analysis comparing pediatric and adult GIs ($P = 0.388$). In terms of age to initiate transition and complete transfer of care from the pediatric to the adult domain the mean age was 16.2 ± 1.46 years and 18.2 ± 1.16 respectively amongst all respondents (Table S2). On subgroup analysis, pediatric GI believed transition should start earlier than adult GI

Table 1 Demographics of respondents

	# Of respondents (total <i>n</i> = 77)	Percentage
Profession		
Adult Gastroenterologist	47	61.0%
Peds Gastroenterologist	16	20.8%
Inflammatory bowel disease nurse	14	18.3%
Practice setting		
Academic center	44	57.1%
Hospital setting	32	41.6%
Outpatient	1	1.3%
Experience		
< 5 yr	18	23.7%
5-10 yr	18	23.7%
> 10 yr	40	52.6%

with mean ages of 15.4 ± 1.41 vs 16.7 ± 1.27 years ($P = 0.003$). Age of transfer completion was similar between adult and pediatric GIs with mean ages of 18.2 ± 1.25 and 18 ± 1.1 respectively ($P = 0.47$).

Adequate preparation for transition

The majority of respondents (58%, $n = 45$) felt that patients were inadequately prepared prior to being transferred from the pediatric to the adult system. This held true with stratification as pediatric ($n = 11/16$, 68.8%) and adult GIs ($n = 25/44$, 56.8%) equally felt that patients were inadequately prepared for ($P = 0.4$). Amongst all respondent's lack of maturity ($n = 46$, 60%) and independence of the patient to advocate for their needs ($n = 40$, 51.9%) were the 2 general domains attributed to the perceived inadequate preparation. In terms of specific factors the following were rated as the most important on the Linkert scale (mean score > 4.5): Patient's knowledge of IBD in general (mean = 4.6) and their particular disease (site affected, medication history, treatment side effects etc.) (mean = 4.6), patient responsibility in taking their medication (mean = 4.7), partaking in discussions during doctor visits (mean = 4.7), being able to recognize when their disease may be active and who to contact (mean = 4.8) and understanding the impact of tobacco and drugs on their condition (mean = 4.6) (Table S3)

Tools to improve transition

A significant amount of adult GIs (37%, $n = 17/46$) stated they do not receive enough information regarding new incoming IBD patients from the referring pediatric GIs.

The vast majority (82.6%, $n = 38/46$) of adults GIs prefer to obtain a chart summary prior to the first visit as opposed to at the moment of the first rendezvous.

Among a variety of tools listed which could potentially be implemented by the transition network in Québec (TRACC), a transition program (77.3%, $n = 59/76$) and medical summaries (76.2%, $n = 58/76$) were felt to be the most important. On subgroup analysis 71.7% of adult GIs and 93.8% of pediatric

GIs felt that a transition program would be a useful tool ($P = 0.07$) with 84.7% and 62.5% respectively choosing medical summaries as important tools ($P = 0.06$). A structured educational day on transition care for patients and their families (47.4%, $n = 36/76$) was also considered useful. A checklist prior to the first adult visit was also considered important (54%, $n = 41/76$). Surprisingly a dedicated transition clinic, which was not clearly defined to respondents but rather listed as a response (32.9%, $n = 25/76$) was not perceived to be as important as some of the other tools amongst all responders (Table S4). However on subgroup analysis it became apparent that this was a more important tool amongst pediatric GIs. Only 21.7% of adult GIs compared to 68.8% of pediatric GIs selected dedicated transition clinics as being important in transition ($P = 0.00006$) (Table 2).

Training and resources

The majority of respondents (75.3%, $n = 52/69$) felt that they had adequate training to effectively deal with transitioning patients in IBD. On subgroup analysis it became apparent that IBD nurses felt less prepared compared to both pediatric and adult GIs ($P = 0.005$, $P = 0.02$ respectively). When looking at the adult GIs (78.3%, $n = 36/46$) compared to pediatric GIs (100%, $n = 10/10$) there was a trend towards significance with the adult GIs tending to feel less adequately trained ($P = 0.10$). Sixty percent ($n = 41/68$) of all respondents were interested in more training *via* either workshops (23.5%, $n = 16/68$) or conferences (44.1%, $n = 30/68$).

Amongst all respondents 64.1% (43/67) felt that they had sufficient resources to manage transitioning IBD patients. However there was a significant difference on subgroup analysis between pediatric GIs (90.1%, $n = 10/11$) compared to adults GIs (55.6%, $n = 25/45$) when it came to the opinion of adequate resources available ($P = 0.0016$) (Table 3). With respect to adequate resources no specifics were detailed, rather this was a general feeling amongst respondents.

DISCUSSION

Our survey of Quebec HCPs working with IBD patients reinforces the notion that a standardized structure for transition is felt to be important. It revealed specifically what HCPs felt were patient related factors that limit effective transition, emphasized the significance of having a dossier summary and identified that a transition program, medical summaries, and potentially a dedicated educational day for patients if routinely implemented might be able to improve transition care in Quebec.

Similarly to previously conducted studies, our survey revealed similar results with respect to patient related factors that are most important for successful transition, including patient's knowledge of their condition and their independence in managing their disease with

Table 2 Select subgroup analysis between adult and pediatric gastroenterologists

	Adult	Pediatrics	P value
Importance of transition (moderately or very important)	95.70%	100%	0.39
Age related questions			
Mean age to initiate transition	16.7	15.4	0.003 ¹
Mean age to complete transfer of care	18.2	18	0.47
Are patients well prepared for transition?	56.80%	68.80%	0.4
Transition tools			
Transition programs	71.70%	93.80%	0.07
Medical summaries	84.80%	62.50%	0.06
Transition clinics	21.70%	68.80%	0.0006 ¹
Pre rendezvous checklists	47.80%	56.30%	0.56
Training and resources			
Adequate training	78.30%	100%	0.1
Sufficient resources	55.60%	90.90%	0.0016 ¹

¹Variable statistically significant with *P* value < 0.05.

Table 3 Training and resources

	Respondents	Percentage
Adequate training (<i>n</i> = 69)	52	75.30
Interested in more training (<i>n</i> = 68)	41	60.00
Training <i>via</i> workshops (<i>n</i> = 68)	16	23.50
Training <i>via</i> conferences (<i>n</i> = 68)	30	44.10
Sufficient resources (<i>n</i> = 67)	43	64.10

adequate self-management skills^[11-13]. Currently there is limited evidence in the literature of improved objective clinical outcomes in patients with IBD who partake in a structured transition program^[9]. However, there is substantial objective evidence that has shown that transitional care can improved clinical outcomes in other pediatric chronic diseases such as diabetes mellitus type 1 and in liver transplant patients^[19-22]. By comparison one can stipulate that *via* transition care in IBD their lies significant potential in improving outcomes such as decreasing rate of hospitalization, improving medical compliance, and even improving other objective outcomes. Further studies focused on IBD related transition care are warranted to demonstrate this.

In the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPHAGN) position paper one of their key recommendations was that the pediatric GIs provide a medical summary to their adult colleagues prior to the first consultation with them^[6]. This study reveals that despite these recommendations a substantial proportion of adult GIs (38.2%) feel that they obtain inadequate information prior to their first encounter. No published or collected data currently exists in Québec about what percentage of adult GIs obtain summaries prior to or at the time of transfer of care. In terms of specific tools identified transition program and medical summaries were the two identified in our survey as important for successful transition care. Examples of such tools exist such as My Health Passport developed at the University of Toronto that serves as succinct summary of a multitude of

chronic pediatric disease including IBD that a patient may bring with them to any encounter with health care professionals^[23]. This tool was designed to be completed by the patient thereby providing the opportunity of the transitioning adolescent to educate themselves while encouraging independence^[17]. The implementation of a tool such as My Health Passport has the dual benefit of acting as a dossier summary for the adult GI and as a method of improving knowledge and inspiring independence.

Respondents also identified a checklist pre 1st adult visit (52.2%) and a "readiness checklist" (39.2%) as other important tools, which provide potential in assisting transition. The TRxANSITION tool created at of the University of North Carolina serves the purpose of being a "readiness" tool with the goals of identifying whether or not a patient is adequately prepared to transition to adult care^[18]. This tool also assists in identifying particular aspects that need to be addressed for transition care optimization.

As was the case in Hait *et al.*^[11] survey ours identified that a proportion of adult gastroenterologists (21.7%) felt they were inadequately trained to manage the population of transitioning IBD patients. Our data also showed that despite a high proportion of respondents felt they were adequately trained (60%) the majority of them were interested in more training *via* conferences or workshops (67.6%) The survey also highlighted an important difference between adult and pediatric GIs when it comes to the availability of resources (55.6% vs 90.9%, *P* = 0.002). This finding is consistent with what is seen in the real world practice of many adult GIs in Quebec where additional resources such as Registered Dieticians, IBD nurses, psychologists are more difficult to access in comparison to pediatrics. By implementing a standardized program for transition care there may be potential to facilitate the ability to access additional resources in the adult system.

Our study had a number of limitations. As with any survey study ours was limited by non-response bias given the response rate of 28.2%. This has the

potential of selecting out HCPs who may place less of an importance on transition care. The small sample size of the survey also limits our study's strength. In addition our study may be limited in interpretability in other geographical locations as it was intended on only assessing the current status in Quebec. Our survey was solely focused on the health care provider perception. It would be interesting to use our compiled data in conjunction with a patient based perspective which may offer the best opportunity to more clearly identify exactly where to focus our resources and which tools may be most useful in improving transition care.

As described in previous studies, our survey reinforces the importance of a transition program, education for young adult IBD patients and the need to improve communication between adult and pediatric GIs. A structured and standardized transition network offering appropriate and applicable tools is the cornerstone to optimize adherence to transition tools and ensure a genuine clinical impact for a successful transition. Further studies are warranted which will likely provide additional objective evidence of the importance of effective transition care.

COMMENTS

Background

Inflammatory bowel diseases (IBD) are showing a rising incidence and prevalence in many areas of the world. Therefore, there is an inevitable need to manage this growing population and the chronic nature of the disease mandates to establish effective means of coordinating efficient transition care from the pediatric to the adult health care domains.

Research frontiers

To date there is minimal data on the perception of transition and transfer of care of IBD patients from pediatric to adult care. Improved objective outcomes with amelioration of transition care have been demonstrated in other chronic diseases spanning pediatric life and adulthood.

Innovations and breakthroughs

As with previous survey studies looking at transition care in IBD the authors' study found that there is a lack of communication between pediatric and adult gastroenterologist with suboptimal transfer of information. This study compared pediatric and gastroenterologists and revealed significant differences between the two groups' perspective of transition care. Notably it identified a significant discrepancy in terms of resource availability.

Applications

Similar to previous studies the authors' survey reinforces the importance of a transition program, education for young adult IBD patients and the need to improve communication between adult and pediatric gastroenterologists. A structured and standardized transition network offering appropriate and applicable tools has the potential to offer a genuine clinical impact for a successful transition. The idea of focusing more resources on transition of care to improve objective outcomes is applicable to many diseases and spans many different health care systems.

Terminology

Transition is defined as a process that spans before and after the transfer of care. Transfer of care is the formal process of transferring the care of a given patient from one health care professional to another.

Peer-review

The study was conducted by assessment of the survey among 136 health care

professionals involved in caring for IBD patients. The findings revealed that the pediatric patients were inadequately prepared for the transition, thus indicating the importance of an educational program for young adults with IBD.

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