

Original Article

Paediatric to Adult Transition of Care in IBD: Understanding the Current Standard of Care Among Canadian Adult Academic Gastroenterologists

Noor Jawaid, MD, FRCPC¹, Thurarshen Jeyalingam, MD, FRCPC², Geoffrey Nguyen, MD, PhD, FRCPC, AGAF^{2,3}, Natasha Bollegala, MD, MSc, FRCPC^{2,4}

¹Gastroenterology Residency Training Program, Department of Medicine, University of Toronto, Toronto, Ontario, Canada; ²Division of Gastroenterology, Department of Medicine, University of Toronto, Toronto, Ontario, Canada; ³Division of Gastroenterology, Department of Medicine, Mount Sinai Hospital, Toronto, Ontario, Canada; ⁴Division of Gastroenterology, Department of Medicine, Women's College Hospital, Toronto, Ontario, Canada

Correspondence: Natasha Bollegala, MD, MSc, FRCPC, Division of Gastroenterology, Department of Medicine, University of Toronto and Women's College Hospital, 4th Floor 76 Grenville Street, Toronto Ontario M5S 1B2, Canada, e-mail: natasha.bollegala@wchospital.ca

Abstract

Background: The optimal form of health care delivery for paediatric to adult inflammatory bowel disease transition of care is unknown. The primary purpose of this study was to establish current standard of care across Canada among adult gastroenterologists.

Methods: Adult gastroenterologists interested in transition care were identified. Twenty-five anonymous surveys and 17 semistructured interviews representing 9 adult gastroenterology centers across 6 provinces were completed. Questions focused on the transition process, referral practices, information transfer and access to multidisciplinary resources. The need for expert guidance and transition-related quality indicators were identified. The interviews were audio-recorded, transcribed and coded in duplicate for qualitative thematic analysis.

Results: Transition practices included the following: transition clinic ($n = 4$) versus direct transfer ($n = 5$). Most transition patients were referred to academic centers. Transfer volume per center ranged from 12 to 100 per year. Transfer of information was optimized with shared electronic medical record and comprehensive referral package. The majority of the programs lacked consistent access to a multidisciplinary team. The strongest attributes related to health care provider interest in transition and complete information transfer. Areas for improvement included increased resource allocation: financial, logistical and personnel. All agreed that a consensus-based guideline for adult phase of transition would be beneficial. Potential quality indicators included adherence to care, depression/anxiety scores and patient knowledge.

Conclusions: This Canadian study of adult gastroenterologists revealed that while practice patterns vary, most agree that a transition clinic with access to multidisciplinary resources would be beneficial. A consensus-based guideline and quality indicators to assess performance may standardize the adult phase of transition and optimize outcomes.

Keywords: *Canada; Inflammatory bowel disease; Paediatric to adult; Patient transfer; Transitional care*

Introduction

Transition to adult care is a common scenario as up to 25% of inflammatory bowel disease (IBD) patients have paediatric-onset disease. The age of 18 is used across Canada as an administrative marker of change from paediatric to adult health care (1). Young adult patients with IBD have unique concerns: gaining independence from caregivers, placing faith in new health care providers and managing the impact of their disease on life itself (2).

Literature focusing on the adult phase of IBD transition is limited in its depth and scope. Trivedi et al. focused on the adult gastroenterologist's perspective citing unique challenges in providing care for the transitioning IBD patient including more complex disease states, increased radiation-induced malignancy rates, sexual and reproductive health concerns and a greater socioeconomic burden on these patients due to life-long chronic illness (3). They also discussed barriers to transition including lack of universal access to structured transition programming, incomplete transfer of health information, no standardized age for transfer and lack of health insurance coverage (3).

A needs-assessment survey was completed in Quebec, Canada, of paediatric and adult gastroenterologists and IBD nurses. The majority of the respondents (97%) agreed that a structured transition in IBD would be beneficial and that patients are inadequately prepared for transition (4).

The primary purpose of this study was to understand current paediatric to adult IBD transition and transfer practice patterns across Canada. Our secondary aims were to (i) perform a Canada-wide needs assessment focused on the adult gastroenterologist, (ii) to determine the need for a consensus-based expert statement to guide practice and (iii) to identify related quality indicators.

Methodology

A propulsive sampling strategy was employed. While patients with paediatric-onset IBD can be transferred to either academic or community settings, it is thought that the more complex patients, and in some provinces most patients, are preferentially transferred to adult academic centers (5). Twenty-eight adult gastroenterologists with an interest in paediatric to adult IBD transition of care were identified via university division heads and national IBD clinical networks. This group was approached via e-mail to complete an online anonymous survey. At the time of survey completion, participants were invited to contact study coordinators to arrange a follow-up in-depth semistructured interview.

Ethics approval was not sought for this project as it was considered a national practice audit for physicians and quality improvement in orientation. Consent was considered implicit with completion of the survey. Explicit verbal consent was acquired prior to each interview.

Survey

A 10-question online survey was created (Supplementary Appendix 1). Questions addressed issues and themes elicited from a focused literature review. The major focus was current transition policies and practices, the participant's ideal transition program. Question formatting included multiple choice answers as well as short-answer. The first wave of survey dissemination was completed via e-mail with a reminder e-mail sent 2 weeks after the initial e-mail. Consent was considered implicit with the completion of the survey. No identifying information was obtained during data collection and no sensitive or private information related to specific patients, providers or centers was elicited.

Statistical software was used to compile and analyze the answers. Thematic analysis was performed by the research team on the short-answer responses. Qualitative research methodology was reviewed with a senior methodologist. An inductive survey process was used. Based on the prominent themes in the first wave, a second expanded 16-question online survey was created allowing iterative incorporation of additional issues identified by study participants. A second wave was disseminated to additional Canadian adult gastroenterologists (Supplementary Appendix 2). These responses were then combined with original survey results to perform a comprehensive qualitative analysis.

Interviews

A 16-question interview script was created based on literature review and survey answers. This included questions regarding models of transitional care, information transfer practices, strengths and weaknesses of current standards and potential quality indicators for such programs. Canadian adult gastroenterologists were recruited via their initial recruitment e-mail. Explicit verbal consent was obtained. Identifying information was not recorded or redacted. Interviews were conducted in person or via telephone. Audio recordings were transcribed.

Qualitative thematic analysis was completed (6,7). Familiarization of the raw data was done, studying the transcripts for key ideas and recurrent themes. A thematic framework was created based on the literature review and new themes raised by participants. Applying inductive analysis, a second expanded 20-question interview script was created and a second wave of additional participants was recruited. Transcripts were processed using the technique of cutting and sorting in order to determine overarching themes (6,7). Two coders completed thematic analysis separately; then compared their thematic frameworks. All major themes were agreed upon by the two coders. When any discrepancies arose, final analytic strategy was decided upon by consensus with additional input from the research lead physician. Thematic saturation was achieved.

Results

Survey

The total number of survey responses from both waves was 25 (12 responses in first wave, with an additional 13 in second wave). The overall response rate was 89% (25/28). Almost all (24/25) of the respondents reported that <50% of their practice was comprised of transition IBD patients.

Respondents characterized their current paediatric to adult IBD transition practice. Only 40% (10/25) of the participants reported a formalized IBD transition of care policy or program at their institution. There was a wide variation in the description of transition programs from informal agreements between paediatric and adult care providers ($n = 2$) to structured overlapping transition periods ($n = 3$) with a joint appointment and a dedicated multidisciplinary team ($n = 2$).

Respondents were asked about transition-related needs. Those without a current program or policy ($n = 15$) all agreed that a structured approach to transition would be beneficial. A transition policy would *'help ensure compliance with therapy, avoid exacerbations of disease activity and reduce the levels of anxiety experienced by patients and families when it comes to the transition process'*.

In the absence of expert advice on the preferred characteristics of a transition program, respondents identified five requirements: dedicated nurse practitioner, multidisciplinary team, overlapping care during the transition period between paediatric and adult providers, optimized communication and a dedicated transition clinic (Table 1). A dedicated nurse practitioner was seen as serving many important roles including triaging referrals and serving as the main point of contact for patients and families. An expanded multidisciplinary team composed of mental health worker, social worker, dietician and pharmacist would ideally be readily available through a transition program. Each of these areas are important in addressing a holistic approach to IBD transitional care. An overlap of care between paediatric and adult providers was noted to make information transfer more concise and provide reassurance to patient and family that their health care plan was agreed upon by all parties. Optimized communication between patients, families and health care providers made for a more complete transfer experience. This included concise patient chart transfer, explicit information provided by transition program to patients regarding their transfer process and the new practice and what to do when patients need help. In order to centralize the above components, a dedicated transition clinic was stated by majority of participants to be important and encourage cohesive care.

Interviews

A total of 17 adult gastroenterologists were interviewed from 9 major academic centers across 6 provinces.

When asked to characterize their current practice, participants estimated from memory the volume of patients undergoing paediatric to adult transition at each centre to range

widely from 12 to 100 per year. The vast majority of patients were transferred to academic centers for adult care, according to the adult gastroenterologists interviewed (5).

Information Transfer Practices

Information transfer in the form of a summary letter from the paediatrician was standard practice at seven of nine centers. The content of summary packages varied but common elements included a succinct medical history, medication regimen and endoscopic investigation results. A shared electronic medical record system between paediatric and adult care providers was present at six of nine centers and was cited as a positive factor for managing information deficits. Minimal written information regarding the transition process was provided to patients as only two centers provided hard copy resources to patients. However, every center commonly provided the following electronic resources to patients wanting to learn more about their disease: Crohn's and Colitis Canada, Crohn's and Colitis Foundation and Trusted Therapies. These websites cover a range of topics such as reproductive health, balancing school with symptoms and peer relationships, etc. The former two also offer direct contact to other patients and their families living with IBD in the form of in person, over-the-phone and online support groups.

Models of Care in Paediatric to Adult Transition

Most adult gastroenterologists tried to facilitate a first consultation within 6 months of referral. Visits within the first year of transition to adult health care were intended to be more frequent (every 3 to 6 months) and longer in duration (1 hour to include time for allied health team support). Transition practices were divided into a transition clinic ($n = 4$) versus direct transfer to an adult gastroenterologist ($n = 5$). Transition clinic was defined by two distinct protocols. The first was a clinic run jointly by paediatric and adult gastroenterology services where new patients were seen concomitantly once, often along with a multidisciplinary team before they transferred completely to adult care ($n = 3/4$). The second design involved an overlapping of separate appointments with paediatric and adult gastroenterologists over a variable period of time ($n = 1/4$). Generally, transition patients would meet their adult gastroenterologist once prior to their last visit with their paediatric care provider before transferring completely. This provided patients the opportunity to see their providers separately and voice any concerns they had. The frequency of these joint clinics varied widely from more than once per month to three to four times per year. No adult practitioners had a standardized method to assess transition readiness either before transfer or once a patient was under adult care. Assessing transition readiness was cited as being a paediatric initiative when and if it took place at all. There was no formalized strategy to address the needs of patients identified as unprepared for transition/transfer once they had entered adult care.

Table 1. Themes relating to the ideal paediatric to adult IBD transition of care program

Theme		Quotes from individual survey participants
Dedicated Nurse Practitioner	Proposed duties: triage referrals, serve as a point of contact for patients and families	“A dedicated nurse practitioner that follows patients through transition”
Multidisciplinary Team	Proposed composition: mental health worker, social Worker, dietician, pharmacist	<p>“[Our] main concern is that we don’t have the relevant resources i.e. no dedicated IBD psychologist, lack of easy access to dieticians, social work, pharmacist”</p> <p>“[We] need more ancillary services in the adult clinic. We are VERY lean for allied health providers!”</p> <p>“[We need] mental health worker[s] as part of the team. [We need] social worker[s] as part of the team to help with financial issues as they pertain to medications, helping with school and occupational planning, helping with complex family dynamics”</p>
Overlapping Care during the Transition Period	Proposed format: joint appointments with paediatric and adult gastroenterology care providers, early acquisition of complete medical record from paediatric team	<p>“Transition should be over time, if possible, with some overlap [between pediatric and adult healthcare providers].”</p> <p>“[It is] useful to have structured summary of IBD history from [the] paediatric service”</p> <p>“Joint pediatric [and] adult visits for patients with high needs (ex. risk of non-compliance, complex psychosocial situation)”</p> <p>“Complete referral package received upon referral to ensure that patients are triaged accurately”</p> <p>“Combined electronic patient record [EPR] between pediatric and adult [systems]”</p>
Optimized Communication	Involved parties: patients, families, health care providers	<p>“More communication between staff and parents. For example, pamphlets explaining the process”</p> <p>“Education series for patients and parents so that patients can build more autonomy with regards to their care”</p> <p>“Meeting patients prior to transition”</p> <p>“Written information of the adult service with staff pictures, roles contact details for the patient and the family as a welcome information.”</p>
Dedicated Transition Clinic	Composed of the above resources	“Overall adult care providers often work alone and do not have ready access to multi-disciplinary resources. Therefore it can be difficult to match the level of support they were receiving [in pediatric care]. This can be frustrating for parents and patients but also demoralizing for adult care providers who feel like they are providing an inferior level of care to their pediatric counterparts given these resource limitations.”

The majority of the adult gastroenterologists appreciated parents being present for the first visit but tried to ensure they also had one-on-one time with their patient so they slowly became more autonomous. All, but two centers, had access to an IBD nurse but the majority lacked consistent access to a multidisciplinary team including social work, dietician and psychologist. Sedation practices were nearly universal in transitioning to conscious sedation. Anaesthesia-supervised propofol sedation was rarely used or offered in the adult setting.

Four centers endorsed their particular model to be used elsewhere. The remaining five centers conceded they were unfamiliar with other models across the country, hence unable to compare. There was also disagreement regarding whether every transitioning IBD patient should undergo a formal transition process. Through our iterative process, of the 10 gastroenterologists who addressed the issue, 7 agreed that all IBD transition patients should undergo a structured transition clinic or process. The other three stated that only ‘high risk’ patients required an official transition process. ‘High risk’ was

defined by having complex disease (i.e., on biologics) and psychosocial issues contributing to higher use of allied health and longer assessments.

Strengths and Weaknesses of Current Models of Transition Care

The strongest perceived attribute of a program was related to dedicated health care providers interested in paediatric to adult IBD transition. Adult gastroenterologists also stated that complete and timely transfer of information from paediatric colleagues was critical.

Areas for improvement included increased resource allocation—a lack of financial resources was cited as negatively impacting patient care (inability to hire allied health professionals for clinics and hospitals or to rent space to run transition clinics). There were also infrastructure concerns such as not having protocols for admitting newly transitioned patients to a paediatric versus adult ward. The area most lacking cited by all interviewees was consistent access to multidisciplinary resources especially in comparison to their paediatric colleagues.

Sixteen of the 17 adult gastroenterologists interviewed agreed that a consensus-based expert position statement on transition practices would be helpful in Canada for guiding transition practices after age 18. However, many expressed concerns regarding the lack of high-quality evidence in this area.

Potential quality indicators by which to evaluate current and future transition practices were discussed in the interviews and thematic analysis elicited three major categories: disease-specific, patient-specific and provider-specific. Disease-specific quality indicators were the quantitative aspects of transition such as health care utilization, use of steroids and need for surgery, particularly within the first year of transition. Patient-specific factors related to qualitative measurements such as quality of life, knowledge of their medical history and adherence to treatment plan. Provider-specific indicators focused on the logistics of the transition process including information transfer and time to first visit and adherence to guidelines for treatment (Table 2).

Discussion

This is the first study to perform a focused adult-oriented nation-wide characterization of transition practices and related needs assessment from the perspective of adult gastroenterologists providing paediatric to adult transition of care in IBD. Participants revealed a wide variety of current transition practices, a broad need for increased access for multidisciplinary resources and a need for further guidance on how to provide high-quality care in this area as well as what metrics to use.

Our thematic analysis elicited several areas in IBD transitional care practices that warrant further consideration. *Preparing for transfer of care:* Assessing transition readiness is not common practice in adult care and there is a lack of knowledge surrounding available tools such as the Transition Readiness Assessment Questionnaire (TRAQ) (8). The information transfer process itself is not consistent however, it is well recognized that a comprehensive summary of a patient's disease, treatments and investigations is critical to providing informed care. *Health service delivery:* Although transition practice patterns vary across Canada, a common theme supported by survey and interview participants is the utility of a dedicated transition clinic with access to multidisciplinary resources. Despite this, less than half of the major academic IBD centres in Canada practice with this model. An IBD nurse was cited as a critical element serving several roles: (i) first point of contact for patients with questions and concerns, (ii) major resource for patient information regarding their disease and treatment, and (iii) liaison between the adult gastroenterologist and the patient. Other allied health members such as psychologists and dietitians were also noted to be important but commonly difficult to access.

The current literature on paediatric to adult transition in IBD has been dominated by the paediatric perspective (1). The NASPGHAN consensus document in this area outlines four major recommendations for successful transition: '(i) Seeing adolescent patients without their parents to build a relationship that promotes independence and self-reliance; (ii) Discussing with the patient and family the benefits of transition to an internal medicine gastroenterology practice; (iii) Developing a relationship with an adult gastroenterologist who is knowledgeable in caring for young adults with a history of childhood-onset IBD; (iv) 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.' These recommendations have been incorporated into several large paediatric Canadian IBD programs including the SickKids Good To Go transition program and the BC Children's OnTrac program (9,10).

Despite this direction, Bensen et al. showed in a national paediatric gastroenterology survey that there is tremendous variability in practice across all diseases but especially IBD (48% of respondents) (11). Gray et al. also recently showed that only 50% of American paediatric gastroenterologist survey respondents were familiar with current recommendations and less than 1% based their practices entirely on them (12).

There has been very little guidance provided to adult health care providers on how to best deliver health care to patients with paediatric-onset chronic disease transitioning to adult care. This is especially the case for IBD. Structured transition programs have been shown to improve patient outcomes

Table 2. Preliminary quality indicators for assessing paediatric to adult transition of care by adult gastroenterologists

Proposed quality indicator	Representative quotations	
Disease-specific factors	<p>Health care utilization in the first year of transition (e.g., Emergency department visits, Hospital admissions)</p> <p>Acute flares of IBD</p> <p>Steroid use</p> <p>IBD-related surgery</p>	<p>“The rate of flare in the first two years after transition could be due to non-compliance, not being seen or being lost to follow up or delayed emergency visits. Because that’s probably a surrogate marker for whether or not they’re taken care of”</p> <p>“Hospital admissions within a year of transition, surgery within a year of transition, a course of steroids within a year of transition. Those are all indicators of something has changed during that critical period.”</p>
Patient-specific factors	<p>Patient satisfaction</p> <p>Quality of Life</p> <p>Adherence to treatment</p> <p>Attendance at ambulatory gastroenterology visits</p>	<p>“I think post-transition... I wonder if there’s a drop off in attendance or for infusions, just picking up their Humira injections and things like that or even filling their prescriptions.”</p> <p>“Patients report outcomes, as in, were they happy with it? Like were they respected, what did they feel... Because I think that if they feel disrespected, they won’t come back”</p>
Provider-specific factors	<p>Time to first post-transfer ambulatory gastroenterology visit</p> <p>Completeness of information transfer from paediatric gastroenterology</p> <p>Adherence to IBD treatment guidelines</p> <p>Adherence to age-appropriate general health guidelines</p>	<p>“Certain aspects of the actual letter or referral in terms of basic information that might be relevant – first scope, extent of disease, pathology report and relevant imaging as well.”</p> <p>“Continuing to follow the right guidelines for different interventions that you do with young adults – whether it’s vaccinations or monitoring the appropriate levels of whatever needs to be monitored.”</p>

in other paediatric-onset diseases such as Type 1 Diabetes Mellitus (T1DM), Cystic Fibrosis (CF) and Congenital Heart Disease (CHD) (13–15). A systematic review on youth with T1DM undergoing paediatric to adult transition showed that structured programming led to reduced episodes of severe hypoglycemia and Diabetic Keto-Acidosis (DKA) as well as improving or maintaining HgA1c levels post-transfer (16). A Canadian CF transition program showed improved outcomes in transition readiness, education and self-reported satisfaction scores after undergoing a three-part transition program (17). An education-targeted transition program led to significant improvements in self-management and cardiac knowledge scores among CHD patients (18). All three of these paediatric-onset diseases have standardized transition protocol guidelines available for both paediatric and adult specialists to implement and follow (13–15).

While there is little literature to support one transition model over another, a number of transition tools and strategies have been reported. The University of Hull group in the United Kingdom completed an RCT enrolling half of the participants in a formalized transition program and half without. The transition program consisted of joint consultations with adult and paediatric gastroenterologists

starting at age 15 to 16. They also received multidisciplinary support from IBD nurse, dietician and clinical psychologist as needed. All participants received disease-specific education and individualized transition plans created. They underwent a global assessment of suitability for transfer based on the opinion of both paediatric and adult care providers but no specific validated tool was used to assess readiness. The study authors showed that the control group required more surgeries and hospitalizations within the first 2 years of transition (46% versus 25%). The intervention group had higher rates of clinic attendance, medication adherence and achieved a higher proportion of their growth potential (19). Other studies have focused on determining what issues a transition program should address. Rosen et al. found that age >24 was the most correlated readiness factor for transition and suggested the medication management portion of the transition readiness assessment questionnaire (TRAQ) could help identify patients at risk for nonadherence independent of age and gender (20). A separate investigator group used the free online application ‘MyHealth Passport’ for IBD during paediatric to adult transition to evaluate disease knowledge in patients aged 14 to 18 years and found that this tool could be used as a resource to educate and instill independence (21).

The major strength of this study was its broad scope. Compared to studies done previously, this study facilitated a nation-wide comparison enhancing our understanding of the current standard of care and ongoing need. Our mixed-methods strategy allowed an in-depth analysis of participant responses. The decision to use inductive analysis ensured we reached thematic saturation and helped broaden our initial a priori study design.

A potential weakness of our study was that the generalizability of our findings is likely limited to Canada as this health care system is unique. Canada provides universal health care coverage for physician services and this causes particular constraints on resources and the availability of health care providers. A provincially mandated transfer of care occurs at age 18 with limited flexibility. Additionally, the methodology used to recruit participants including contacting Gastroenterology division heads and using professional networks may have missed adult care providers who practice primarily in the community setting. This national patient population is unique, especially given that Canada has one of the highest rates of IBD worldwide and in certain centers have a diverse ethnic composition (22). Despite this, the study authors believe that there are major similarities across countries, health systems and other childhood-onset chronic diseases allowing the lessons drawn from this study to be applied to other settings and inform further research.

Two major areas were identified as future directions from the findings of our study. As all participants in this study agreed, a consensus-based position statement could serve as an impactful way forward in standardizing care and optimizing outcomes, recognizing the limitation in high-quality content-specific evidence. A consensus-based process to develop quality indicators in paediatric to adult IBD transition of care could be important for evaluating models of care and improving quality over time.

Conclusion

The transition period from paediatric to adult health care in IBD can be a difficult path to navigate by all involved and an area requiring more attention. This study assessed IBD transitional care practices and policies across Canada's highest volume IBD centers. This Canadian national representative survey focusing on adult gastroenterologists revealed that practice patterns vary. The development of quality indicators and consensus-based direction for adult gastroenterologists in this area are important steps forward in achieving high-quality consistent care. Understanding the advantages and short-comings of current transition policies will help guide our future efforts in creating a consensus-based guideline for adult care providers in IBD transition.

SUPPLEMENTARY DATA

Supplementary data are available at *Journal of the Canadian Association of Gastroenterology* online.

No ethical approvals were required

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