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A REVIEW OF PEDIATRIC TO ADULT TRANSITION OF CARE IN INFLAMMATORY BOWEL DISEASE

The Epidemiology of Childhood Onset Inflammatory Bowel Disease

Canada is reported to have one of the highest rates of both incidence and prevalence of inflammatory bowel disease (IBD). Benchimol et al. conducted a population-based cohort study from 1999-2008 using health administrative data from Ontario, Canada, and reported that the prevalence of IBD in Canada in 2008 was 534.3 per 100,000 people (68,017 affected individuals among 12,738,350 Ontario residents).[1] Between 1999 and 2008, the incidence of IBD increased annually in children under the age of 10 (9.7% per year, $p<0.0001$) and in those aged 10-19 (3.8% per year, $p<0.0001$).[2,3]

Coward et al. published a similar population based health administrative data study using data from eight provinces in Canada. In this study the national incidence of IBD was estimated to be 29.9 per 100,000 (95% PI 28.3-31.5) in 2023.ll The incidence of IBD in pediatric patients was found to be increasing (average annual percentage change (AAPC) 1.27%; 95% CI 0.82-1.67). The prevalence of IBD was 843 per 100,000 (95% PI 716-735) in 2023 with forecasted increases (AAPC 2.43%;95% CI 2.32-2.54). In pediatric patients the prevalence in 2023 was 82 (95% PI 77-88) and the forecasted AAPC was 1.91 (1.46-2.31).

According to the 2023 Impact of IBD in Canada Report by Crohn's and Colitis Canada, an estimated 322,600 Canadians are living with IBD, with 11,000 new diagnoses expected in 2023.[4,5]

The global incidence and prevalence of IBD has been rising. In 2011, Benchimol et al. published a systematic review detailing international trends in IBD.[6] The review demonstrated a 60% increase in Crohn's disease (CD) and a 20% increase in ulcerative colitis (UC) across both developing and developed countries. Benchimol et al. also published the results of a health administrative data analysis evaluating children with a diagnosis of IBD between 1999-2010 across five Canadian provinces, which together account for 79.2% of the Canadian population.[7] They reported that incidence of IBD in children aged five and under increased during the study period (annual percentage increase [APC] +7.19%; 95% CI, +2.82% to +11.56%). The prevalence of IBD also increased significantly during the study period (APC+4.56%; 95% CI, +3.71% to +5.42%).[7]

The Dilemma of Transition of Care

Considering its low mortality, children diagnosed with IBD will eventually be required to transition from pediatric oriented health services to adult care. Kaplan et al. provided a thorough explanation of this phenomenon, outlining the compounding prevalence within the context of IBD. With the life expectancy of individuals in the Western world into the 80s and young patients being diagnosed regularly, the prevalence of IBD in the Western world is steadily increasing.[8]

Pediatric to adult transition of care is defined as *"the purposeful planned movement of adolescents* *and young adults with chronic physical and medical conditions from child centered to adult oriented healthcare systems* (Blum 1993).[9]" It is recognized that in pediatric healthcare systems both the child and their care partner participate in the process, with the care partner usually responsible for medical decision making. In the adult healthcare system, there is an expectation of patient autonomy with the experience focused on the patient themselves, with less attention paid to the expectations and needs of their care partner. This divergence in focus and care delivery creates the opportunity for adverse health outcomes. Added to this is the overlap of healthcare transfer of care upon milestones such as completing secondary education, beginning either a vocation or post-secondary education, potentially leaving the family household, and gaining financial independence, all of which can create additional stress and burden to a young adult managing a lifelong, complex chronic disease.

In contrast, transfer of care specifically refers to the handover of care to the adult healthcare team.

Access to Transition of Care Services

The child and adolescent health measurement initiative published data from their 2021-2022 National Survey of Children's Health (NSCH), an American national survey, funded by the Health Resources and Services Administration's Maternal and Child Health Bureau.[10] A total of 104,995 surveys were completed in 2021 and 2022 combined. Across 50 states and the District of Columbia, the estimated percentage of patients who received transition of care services between the ages of 12 and 17 (after application of sampling weights) ranged from 9.8 to 30.5%.[10]

Jawaid et al. conducted a national qualitative survey assessing the access and quality of transition of care resources for children moving from pediatric to adult care across Canada.[11] The study involved targeted sampling of gastroenterologists with expertise in IBD transition care who treat adults. Researchers conducted 25 anonymous surveys and 17 semi-structured interviews across nine adult IBD centres and six Canadian provinces. They reported that four out of five centres offered an IBD transition clinic, with most transition-aged patients being preferentially transferred to an adult IBD centre within a tertiary care academic institution. The number of transition-aged patients transferring annually ranged between 12-100, according to these preferred providers. Challenges during the transition of care period included a consistent lack of access to multi-disciplinary healthcare resources. In addition, participants agreed that a comprehensive referral package and access to shared patient data, for example through a shared electronic medical record, eased the transfer of care process.[11]

Outcomes in Pediatric to Adult Transition of Care in IBD

Traditionally healthcare outcomes have been disease focused, with a focus on endoscopic and clinical remission, and normalization of serological markers of inflammation. There is now a broader understanding that a patient's perceived sense of wellness and overall quality of life is a foundational target outcome that ultimately allows a young person with IBD to achieve their personal potential. Interventions to improve these patient reported outcomes are now a critical component of our approach to IBD care.

Patient and Provider Reported Outcomes

Bihari et al. evaluated definitions of transition success according to patients, parents, and healthcare providers during the transition of care period.[12] Using purposive sampling, they conducted 17 semi-structured interviews with patients, 13 with parents, and 15 with healthcare providers. This process identified several themes that define a successful transition. Key criteria included independent engagement (self-advocacy, taking responsibility for appointments, being aware of health-related events). Active involvement in disease management was also identified, including adherence to treatments, investigations, and coordinating with the healthcare team during disease flares. The development of a supportive and trusting relationship with the healthcare team was identified. A flexible approach by the adult care team is essential, acknowledging the challenges of transitioning from a pediatric healthcare system and the demands of post-secondary programs that might limit attendance or engagement. Providers valued having a comprehensive disease-specific knowledge base. Patients emphasized the importance of a regularly available adult healthcare provider and disease stability.[12]

Transition Related Readiness

One of the key factors thought to encompass the critical skills needed for transition is transition readiness. These skills include self-management, medication and disease-related knowledge, health literacy, and self-efficacy. Johnson et al. conducted a systematic review of factors affecting transition readiness skills in IBD patients that included 16 studies.[13] These factors were divided into provider related, demographic, other, and disease-related factors. Among provider related factors, the duration of the transition (before transfer of care occurred) was positively associated with self-efficacy. Fourteen studies demonstrated a positive association between age and self-management behaviours as well as disease-related knowledge. Three studies have shown a positive relationship between self-efficacy, knowledge, and self-management behaviours. Depression and anxiety were associated with lower self-efficacy, while a family history of IBD was found to be positively associated with self-efficacy. Three studies reported that female gender was positively associated with self-management.[13]

Health Service Utilization

Botema et al. conducted a cohort study using a Dutch insurance database that covered approximately 4.2 million people, or 25% of the Dutch population, from 2007 to 2014.[10] They followed patients aged 16-18 until the age of 19 or when they transferred to adult care. The study reported that steroids and biological advanced IBD therapies were used less frequently in pediatric care, and that there were fewer overall IBD-related hospitalizations while under the care of a pediatric provider.[14]

Zhao et al. used health administrative data in Ontario, Canada from 1998 to 2008 to evaluate IBD-specific and IBD-related outpatient visits, emergency department visits, hospitalizations, and laboratory visits.[15] They compared the relative incidence (RI) in the last two years of pediatric care with the first two years of adult care. The study included 536 patients (388 with CD and 148 with UC). The findings showed that emergency department visits ([CD RI, 2.12; 95% CI, 1.53-2.93], [UC RI 2.34; 95% CI, 1.09-5.03]), outpatient visits ([CD RI, 1.56; 95% CI, 1.42-1.72], [UC RI, 1.48; 95% CI, 1.24-1.76]), and laboratory investigations were all significantly higher in the adult period.

Interventions to Optimize Healthcare Outcomes During Transition of Care.

There is a paucity of level one evidence rigorously evaluating the impact of targeted interventions aimed at improving transition-specific healthcare outcomes.

Bollegala et al. have published the protocol for a randomized controlled trial evaluating the impact of a multimodal intervention to improve the transition of patients with IBD from pediatric to adult care.[16] This type 1 hybrid effectiveness-implementation trial aimed at patients aged 16-17.5 and evaluates the role of a four part model including 1) individualized assessment, 2) a transition navigator, 3) virtual patient skill building, and 4) a virtual education program. The primary outcome is the IBD disability index. This study has not yet entered into the analytic phase and preliminary results are not yet available. In the absence of level one data to support transition programming, this intervention has elected to focus on the role of a transition navigator and a comprehensive transition focused educational platform. This was also the intervention supported by the Canadian Consensus Statements on the Transition of Adolescents and Young Adults with Inflammatory Bowel Disease from Pediatric to Adult Care.

Erős et al. published a systematic review on the transition of care from pediatric to adult.[17] The most commonly studied intervention was the role of a joint visit between the adult gastroenterologist, the pediatric gastroenterologist, the patient, and their care partner. The number of visits, the duration of time over which they occur, and their locations varied across studies. The members of the healthcare team participating in these visits also varied. In some studies, multidisciplinary team members such as dieticians, IBD nurses, and psychologists were present. The purpose of these visits could range from a comprehensive review of the patient's medical history and upcoming treatment plans to disease-specific education and the development of skills such as communication.

Corsello et al. conducted an observational study in Rome, Italy which evaluated the impact of a two-part transition of care process.[18] The first visit took place at the pediatric centre with parents and both adult and pediatric providers present. The second visit occurred at the adult centre. The study included 82 IBD patients with a mean transition age of 20.2 ± 2.7 years. Notably, 75% of participants expressed a positive opinion about this transition strategy. The authors recommended an optimal age range for these visits, prioritizing their occurrence during a period of remission.

Marani et al., acknowledged the limited scope of literature on transition-specific interventions for IBD, and expanded their literature review to include any transition interventions across all pediatric-onset chronic diseases.[19] They identified 26 studies and two broad categories of intervention, which included multidisciplinary transition clinics and transition programs led by facilitators. Both interventions featured elements such as educational interventions, social programs and peer support, enhanced communication strategies, and targeted efforts to improve transition readiness.

Reviews of the literature in this area have identified variability in outcome measurements, and heterogeneity in the measurement scales of these outcomes. They identified a need for greater consistency to identify significant differences and to take subsequent targeted steps to improve the quality of care.

Canadian Consensus Statements on the Transition of Adolescents and Young Adults with Inflammatory Bowel Disease from Pediatric to Adult Care.

Canadian Consensus Statements on the Transition of Adolescents and Young Adults with Inflammatory Bowel Disease from Pediatric to Adult Care.

In the absence of clear evidence, most guideline statements in this area are based on expert opinion and consensus.

Several guidelines in this area have been published. Vernon-Roberts et al. released guidelines for Australia and New Zealand in May 2024.[20] The United Kingdom's IBD transition guidelines were published in 2017 by Brooks et al.[21]

The recent Canadian guidelines were developed by a comprehensive multi-disciplinary group from across Canada, representing a variety of practice settings and incorporating patient partners.[22] They issued 15 statements emphasizing the importance of individualized structured transition programs focused on skill building in behaviour, knowledge, and abilities. The guidelines recognized the need to support care partners during this process of emerging independence and addressed the training needs of adult healthcare providers managing this complex phenotype. Importantly, they identified the role of a primary care provider as a stable figure during a period of change and an important ally in managing adolescent-specific issues that may be unfamiliar to the adult gastroenterologist. The guidelines also emphasized the importance of a comprehensive transfer of care letter from the pediatric care provider.[18]

Conclusions

The transition of IBD patients from pediatric to adult care is a complex process involving multiple stakeholders. An emerging body of literature is exploring effective interventions to optimize healthcare outcomes in this area. Ultimately, gaining an appreciation for the complexities of this period, prioritizing these patients by adult gastroenterologists, and improving transition-specific skills provide the necessary foundation for successful outcomes.

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