crohn's colitis

Name of Clinical Care Pathway (CCP)

Transition of Care in Inflammatory Bowel Disease (IBD)

Objective

To provide practical clinical advice for gastroenterologists involved in the transfer of care of patients with pediatric onset IBD from pediatric to adult care based on the best available literature and clinical tools.

Patient Population

Adolescents and young adults with IBD

Dr. Natasha Bollegala HonBSc MD MSc FRCPC (Women's College Hospital & University of Toronto)
Dr. Nancy Fu MD, MHSc, FRCPC (University of British Columbia)

PACE Inflammatory Bowel Disease Clinical Care Pathways

Highlight Box

- A structured transition process is associated with better outcomes.
- A prospective clinical trial evaluating the role of a transition program involving clinical resources such as a transition navigator and a comprehensive educational program is underway. This CCP will be updated based on the results obtained.
- This CCP is created based on currently available evidence and clinical tools.

These clinical decision support tools were developed by Canadian experts in IBD, based on their interpretation of current evidence and considerations specific to Canadian healthcare. International guidelines from Europe and the United States are available. However, these may reflect regional factors not directly applicable in Canada.

Introduction

Pediatric to adult transition of care is the process of migrating a patient with chronic disease from pediatric to adult care. It requires continuous, coordinated, and comprehensive care while paying attention to the clinical, psychosocial, and educational/vocational needs of adolescent and young adult (AYA) patients. If the transition and transfer process fail, it can lead to an increase in emergency department visits, hospitalizations, medication adjustments, surgeries, adherence and negatively impact quality of life.

Due to the growing number of cases of inflammatory bowel disease (IBD) in children, it has become increasingly necessary to establish a structured transition plan for AYAs. To achieve this goal, the Canadian IBD Transition Network and Crohn's and Colitis Canada joined forces to develop a set of care consensus statements to provide a framework for transitioning AYA from pediatric to adult care. Since then, the Canadian IBD Nurses (CANIBD) have developed an online clinical tool for transition of care with practical tools.

This CCP is primarily based on the March 2022 published Canadian Consensus statements on transition of AYAs with IBD (Bollegala et al., 2022) and also incorporates the results of an updated literature search conducted from June 2019 to July 2022.

<u>Phase 1: Pediatric phase</u>

Clinical

- Identify the IBD transition patient:
  - Age 12+
  - Consider special needs (developmental, pregnancy, psychosocial)
- Discuss goals (treatment, transition, others) and expectations
- Review the transition/transfer timeline
- Review the assessment plan
- Clarify communication strategies

Operational

- Please refer to the TransitionIBD Flowsheet (CANIBD, 2024)
    - Initiate the transfer summary
    - Initiate a transfer checklist

Phase 2: Care transfer

- Identify & initiate referral to adult gastroenterology
    - Be aware of target recipient providers, associated wait times, geographic availability
    - Discuss impending transfer with the patient and their care partners. Consider the discussion points listed in Table 1.

- Send transfer of care summary to the target adult gastroenterologist early (according to local wait times) and clearly indicate the priority of transfer and any time-sensitive issues that need to be addressed early in adult care.

- Adult providers should prioritize transfers of care within 6 months of referral receipt
    - Be aware of age restrictions for local health facilities (ambulatory clinics, hospital admissions, endoscopic procedures, surgical procedures).
    - Consider a more comprehensive handover plan for complex cases (e.g. multi-disciplinary case conferences).

- Ensure continuity of the larger healthcare team
    - Primary care providers (especially for children leaving the care of pediatricians, be aware of local availability) should be aware of the transfer.
    - Health insurance (for medications, stoma devices, etc.) should be up to date. Additional sub-specialists and allied health providers should have a transfer of care plan if appropriate and should be included in the correspondence.

Table 1: Topics to review with AYAs and families regarding adult care

By the pediatric healthcare team before the transfer
Differences in procedural sedation
How to access pediatric medical records
The role of the primary care provider in IBD care
The intended receiving adult gastroenterology health care team and location
By the adult health care team at intake meetings
Expectations related to IBD related care
Collaborative realistic goal setting
Roles of AYA in adult care
Roles of parents/caregivers in adult care
How, who and when to contact the adult healthcare team
How to access adult medical records
Differences in procedural sedation

AYA, adolescents and young adults; IBD, inflammatory bowel disease

Phase 3: Adult phase

- Transition skills assessment
  Consider using the Transition Readiness Assessment Questionnaire (TRAQ) (Rosen et al., 2016) and the TransitionIBD Flowsheet (CANIBD, 2024). The appendix provides a comprehensive listing of available transition skills assessment tools.

- Engage healthcare partners in addressing the healthcare needs of the patient
  Be aware of local allied health resources (e.g. nursing support, dieticians, psychologists/psychiatrists, social workers, etc.).
    - Potential issues to address: Preventative health, contraception, mental health, and monitoring related to advanced IBD therapies.

- Identify and address special populations
  - Young adults who may live elsewhere for occupational or academic reasons
    - Establish an emergency care plan.
    - Consider medication routes of administration that may be more convenient.
    - Discuss local resources such as student health services and local laboratories to assist with ongoing care.
    - Ensure a communication plan that accommodates distance (e.g. virtual care, secure patient messaging systems, etc.)
  - Special needs patients
  - Pregnancy

References

Atreja A, Khan S, Rogers JD, et al.; HealthPROMISE Consortium Group. Impact of the mobile HealthPROMISE platform on the quality of care and quality of life in patients with Inflammatory Bowel Disease: Study protocol of a Pragmatic Randomized Controlled Trial. JMIR Res Protoc 2015;4(1):e23. https://doi.org/10.2196/resprot.4042

BC Children's Hospital. Transition to Adult Care. Accessed January 28, 2021. http://www.bcchildrens.ca/our-services/support-services/transition-to-adult-care

Benchimol EI, Afif W, Plamondon S, Newhook D, Nicholls SG, Lévesque D. Medical summary template for the transfer of patients with inflammatory bowel disease from pediatric to adult care. Journal of the Canadian Association of Gastroenterology. 2022 Feb 1;5(1):3-11. https://doi.org/10.1093/jcag/gwab009

Benchimol EI, Walters TD, Kaufman M, et al. Assessment of knowledge in adolescents with inflammatory bowel disease using a novel transition tool. Inflamm Bowel Dis 2011;17(5):1131–7. https://doi.org/10.1002/ibd.21464

Bollegala N, Barwick M, Fu N, Griffiths AM, Keefer L, Kohut SA, Kroeker KI, Lawrence S, Lee K, Mack DR, Walters TD. Multimodal intervention to improve the transition of patients with inflammatory bowel disease from pediatric to adult care: protocol for a randomized controlled trial. BMC gastroenterology. 2022 May 18;22(1):251. https://doi.org/10.1186/s12876-022-02307-9

Bomba F, Markwart H, Mühlan H, et al. Adaptation and validation of the German Patient Activation Measure for adolescents with chronic conditions in transitional care: PAM® 13 for Adolescents. *Res Nurs Health* 2018;41(1):78–87. https://doi.org/10.1002/nur.21831

Brooks AJ, Smith PJ, Lindsay JO. Monitoring adolescents and young people with inflammatory bowel disease during transition to adult healthcare. Frontline Gastroenterology. 2018 Jan 1;9(1):37-44. https://doi.org/10.1136/flgastro-2016-100747

Carlsen K, Haddad N, Gordon J, et al. Self-efficacy and resilience are useful predictors of transition readiness scores in adolescents with inflammatory bowel diseases. *Inflamm Bowel Dis* 2017;23(3):341–6. https://doi.org/10.1097/mib.0000000000001038

Fu N, Bollegala N, Jacobson K, Kroeker KI, Frost K, Afif W, El-Matary W, Fowler SA, Griffiths AM, Huynh HQ, Jantchou P. Canadian consensus statements on the transition of adolescents and young adults with inflammatory bowel disease from pediatric to adult care: a collaborative initiative between the Canadian IBD transition network and Crohn's and Colitis Canada. Journal of the Canadian Association of Gastroenterology. 2022 Jun 1;5(3):105-15. https://doi.org/10.1093/jcag/gwab050

Ghosh S, Louis E, Beaugerie L, et al. Development of the IBD Disk: A visual self-administered tool for assessing disability in inflammatory bowel diseases. Inflamm Bowel Dis 2017;23(3):333–40. https://doi.org/10.1097/mib.0000000000001033

Gower-Rousseau C, Sarter H, Savoye G, et al. International programme to develop New Indexes for Crohn's Disease (IPNIC) group; international programme to Develop New Indexes for Crohn's Disease (IPNIC) group. Validation of the Inflammatory Bowel Disease Disability Index in a population-based cohort. Gut 2017;66(4):588–96. https://doi.org/10.1136/gutjnl-2015-310151

Hait E, Arnold JH, Fishman LN. Educate, communicate, anticipate—practical recommendations for transitioning adolescents with IBD to adult health care. Inflammatory bowel diseases. 2006 Jan 1;12(1):70-3. https://doi.org/10.1097/01.MIB.0000194182.85047.6a

Horne R, Weinman J, Hankins M. The beliefs about medicines questionnaire: The development and evaluation of a new method for assessing the cognitive representation of medication. *Psychol Health*. 1999;14(1):1–24. https://doi.org/10.1080/08870449908407311

Horne R, Weinman J. Self-regulation and Self-management in Asthma: Exploring the role of illness perceptions and treatment beliefs in explaining non-adherence to preventer medication. *Psychol Health*. 2002;17(1):17–32. https://doi.org/10.1080/08870440290001502

ImproveCareNowTM. ImproveCareNow. Accessed November 30, 2019. https://www.improvecarenow.org

Kelly M, Ferris M, Ford C, Bickford K, Layton B, Kim S. The UNC T.RxA.N.S.I.T.I.O.N. ScaleTM: A tool to measure the process of health care transition for adolescent IBD patients. Inflamm Bowel Dis. 2009;15:S18. http://dx.doi.org/10.1097/00054725-200912002-00050

Kiser SB, Kelly M, Flint R, Sharpless VE, Galanko JA, Kim SC. 192 development and validation of an adherence scale for adolescent patients with inflammatory bowel disease. *Gastroenterology*. 2012;142(5):S-47. http://dx.doi.org/10.1016/S0016-5085(12)60181-4

NASPGHAN. Transitioning a Patient With IBD From Pediatric to Adult Care. Accessed January 28, 2021. https://www.naspghan.org/files/documents/pdfs/medical-resources/ibd/Checklist_PatientandHealthcareProdiver_TransitionfromPedtoAdult.pdf

Nazareth M, Hart L, Ferris M, et al. A parental report of youth transition readiness: The Parent STARx Questionnaire (STARx-P) and Re-evaluation of the STARx Child Report. J Pediatr Nurs 2018;38:122–6. https://doi.org/10.1016/j.pedn.2017.08.033

Rosen D, Annunziato R, Colombel JF, et al. Transition of inflammatory bowel disease care: Assessment of transition readiness factors and disease outcomes in a young adult population. Inflamm Bowel Dis 2016;22(3):702–8. https://doi.org/10.1097/mib.0000000000000633

Shapiro JM, El-Serag HB, Gandle C, Peacock C, Denson LA, Fishman LN, Hernaez R, Hou JK. Recommendations for successful transition of adolescents with inflammatory bowel diseases to adult care. Clinical Gastroenterology and Hepatology. 2020 Feb 1;18(2):276-89. https://doi.org/10.1016/j.cgh.2019.04.063

Tan B, Ong D. Pediatric to adult inflammatory bowel disease transition: the Asian experience. Intestinal research. 2020 Jan;18(1):11. https://doi.org/10.5217%2Fir.2019.09144

Transition IBD Flowsheet template. Canadian IBD Nurses (CANIBD). Retrieved on August 8, 2024, from https://crohnsandcolitis.ca/Research/Canadian-IBD-Nursing/Learning-for-nurses/IBD_TransTools_TransLetter_v5_20220930-FINAL-CANIB.aspx

Vernon-Roberts A, Otley A, Frampton C, et al. Response pattern analysis of IBD-KID: A knowledge assessment tool for children with inflammatory bowel disease. J Paediatr Child Health 2020;56(1):155–62. https://doi.org/10.1111/jpc.14547

Zijlstra M, De Bie C, Breij L, et al. Self-efficacy in adolescents with inflammatory bowel disease: A pilot study of the "IBD-yourself", a disease-specific questionnaire. J Crohns Colitis 2013;7(9):e375–85. https://doi.org/10.1016/j.crohns.2013.02.017

Appendix

Transition-related skills or characteristics and assessment tools

Skills or characteristics	Assessment tools
IBD-specific knowledge	IBD-yourself (Zijlstra et al.,2013) MyHealth Passport (Benchimol et al., 2011) IBD-KID2 (Vernon et al., 2020)
Transition Readiness	Transition Readiness Assessment Questionnaire (TRAQ) (Rosen et al., 2016) Successful Transition to Adulthood with Therapeutics (STARx) (Nazareth et al.,2018) Got-Transition (GoodToGo) (Benchimol et al., 2011) UNC TR(x)ANSITION (Kelly et al.,2009) ON TRAC (BC Children's Hospital, 2021) NASPGHAN Transition Checklist (NASPGHAN, 2021)
Self-efficacy and Self-management	IBD Self-Efficacy Scale Adolescent (IBD-SES A) (Carlsen et al., 2017) HealthPROMISE (Atreja et al., 2015) ImproveCareNow Self-management Handbook (ImproveCareNowTM, 2019)
Functional Status	IBD Disk (Ghosh et al., 2017) IBD Disability Index (IBD-DI) (Gower-Rousseau et al., 2017)
Resilience	Conner-Davidson Resilience Scale (CD-RISC) (Carlsen et al., 2017)
Self-activation	Patient activation measure 13 Adolescent (PAM13 A) (Bomba et al., 2018)
Adherence	Beliefs in Medicine (BMQ) (Horne et al., 1999) MMS-8 (Kiser et al., 2012) MARS (Horne & Weinman, 2002)